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CANCER DETECTION IN WOMEN AND OTHER HEALTH CARE CONCERNS

HEARING

BEFORE THE

COMMITTEE ON LABOR AND HUMAN RESOURCES UNITED STATES SENATE

ONE HUNDREDTH CONGRESS

SECOND SESSION

ON

REVIEWING AREAS OF WOMEN'S HEALTH CARE, FOCUSING ON CANCER DETECTION AND PREVENTION; LONG TERM HEALTH CARE; AND DEPRESSION AND SUBSTANCE ABUSE

JUNE 8, 1988, SALT LAKE CITY, UT

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CANCER DETECTION IN WOMEN AND OTHER HEALTH CARE CONCERNS

FRIDAY, JUNE 3, 1988

U.S. SENATE,
COMMITTEE ON LABOR AND HUMAN RESOURCES,
Salt Lake City, UT.

The committee met, pursuant to notice, at 10:00 a.m., in the Salt Lake County Commission Chambers, 2001 South State Street, Salt Lake City, Utah, Senator Orrin Hatch presiding.

Present: Senator Hatch.

OPENING STATEMENT OF SENATOR HATCH

Senator HATCH. I'm pleased to welcome everyone here today. We will hear from six distinguished experts on three areas of women's health care: First, cancer detection and prevention; second, long term health care and its impact on women; and third, depression and substance abuse.

Now, cancer detection and treatment has come a long way. Fifty years ago no one survived from cancer. Today those frightening statistics have severely changed. In 1987 it was estimated that 480,000 women in this county developed cancer. Utah's rates are about 15 percent lower than the average rates. But most forms of cancer which can affect women can be prevented—either by early detection and treatment or by changing certain lifestyle patterns.

For example, one out of ten women will develop breast cancer in her lifetime, and breast cancer is one of the leading killers among women with 38,000 deaths each year. And cancer of the cervix took the lives of roughly 6,800 mothers, wives, sisters and daughters. However, through early detection and prompt treatment almost 90 percent of breast cancer patients and cervix cancer patients can survive. These are illnesses that we really can prevent.

There are some basic facts that health care experts believe every woman needs to know—like the need for routine testing, such as Pap smears and breast examinations. They will be highlighted today by our first panel of experts.

I'm very pleased to welcome Elizabeth Stack, a television and movie star, who is graciously contributing her time to work with the American Cancer Society. The American Cancer Society is celebrating its 75th Anniversary as the premier organization devoted to preventing Americans from having cancer and to protecting our Americans from having cancer. I am pleased also to welcome Dr. Charles Smart, a world expert on issues relating to early cancer detection and treatment.

[The prepared statement of Senator Hatch follows:]

From the office of

SEN. ORRIN HATCH

Washington, D.C. 20510

Opening Statement - Senator Orrin G. Hatch
Cancer Detection in Women and Other Health Care Concerns

June 3, 1988

I am pleased to welcome everyone here today. We will hear from six distinguished experts on three areas of women's health care: first, cancer detection and prevention; second, long-term health care and its impact upon women; and third, depression and substance abuse.

Cancer detection and treatment has come a long way. Fifty years ago no one survived. Today those frightening statistics have changed. In 1987 it was estimated that 480,000 women in this country developed cancer. Utah's rates are about 15 percent lower. But most forms of cancer which affect women can be prevented -- either by early detection and treatment or by changing certain lifestyle patterns.

For example, one out of ten women will develop breast cancer in her lifetime, and breast cancer is one of the leading cancer killers among women, with 38,000 deaths each year. And, cancer of the cervix took the lives of roughly 6,800 mothers, wives, sisters and daughters. However, through early detection and prompt treatment, almost 90 percent of breast cancer patients and cervix cancer patients can survive. These are illnesses that we can prevent.

There are some basic facts that health care experts believe every woman needs to know -- like the need for routine testing, such as pap smears and breast examinations. They will be highlighted today by our first panel of experts.

I am very pleased to welcome Elizabeth Stack, a television and movie star, who is graciously contributing her time to work with the American Cancer Society. The American Cancer Society is celebrating its 75th Anniversary as the premier organization devoted to protecting Americans from cancer. I am especially pleased to welcome Dr. Charles Smart, a world expert on issues relating to early cancer detection and treatment. Dr. Smart, welcome home to Utah.

Our second panel will discuss another important health care issue -- long term care. America is experiencing a longevity revolution, as 5,200 Americans each day join the ranks of senior citizens. We are enjoying longer and more productive lifespans. While the prospect for a longer life span is good news, it also begets new issues. And, our greatest concern is the health care needs of our seniors.

Examples of financial ruin caused by catastrophic health care costs can be found everywhere. We have all heard the story about an elderly family member who has a lingering illness and is forced to sell his or her home to pay off the mounting hospital, physician, and prescription drug debt not covered by federal or private insurance. And, long-term health care needs is a problem which falls heaviest upon women in our society for one primary reason -- they generally outlive men. They are called on to care for their husband, and then eventually need help for themselves. We need to address this problem.

But the fundamental question which Congress has to decide -- and decide fast -- is what kind of care and assistance can be offered in a deficit ridden era, and in what type of setting should that care be provided. I have advocated expanding home health care services as a primary solution, but I do look forward to the testimony of two experts here today who will describe our current need for services. We will hear the provider perspective from Shauna O'Neil, Director of Salt Lake County Aging Services, as well as from Mrs. Marian Lewis, who herself is a caregiver for her ailing husband and has required care for herself recently.

Our final panel will provide us with insights on the health problems of depression and substance abuse. Approximately 10 million Americans suffer from a depressive disorder. And over the course of a lifetime, one-fourth of women and one-eighth of men in America will suffer from a depressive disorder.

Depression can be as severe and disabling as heart disease. And, like heart disease, depression can be successfully treated. Our primary goal, then, is early detection and treatment. I am pleased to welcome back to Utah, Dr. Lewis Judd, the new Director of the National Institute of Mental Health, to discuss the problems women face as a result of the disease of depression. And, finally, we will discuss legislation to continue the Alcohol, Drug Abuse and Mental Health Block Grant set-aside of 5 percent. This funds state programs which provide services to women who abuse alcohol and drugs. I look forward to testimony by Nikki Lovell, representing Ogden Junior League, who will discuss federal, state, and private sector efforts to expand treatment and prevention programs for women.

In closing, we live in an age of unprecedented medical advances and an increased understanding of disease. Society must continue its support of programs to help us live longer, productive and independent lives. But many illnesses that afflict us are preventable. We need to remind ourselves of the wise saying of Benjamin Franklin, that an ounce of prevention is worth a pound of cure -- that is a rule which directly applies to today's hearing. It is my hope that today's hearing, which will become a permanent part of the United States Senate's record, will help Americans have a greater education on the ways to prevent disease in America. I look forward to the testimony presented here today.

Senator HATCH. Dr. Smart, welcome home to Utah. We're really happy to have you here.

Miss Stack, we'd like for you to take the witness chair, and please begin. We're interested in what you have to say.

STATEMENTS OF ELIZABETH STACK, AMERICAN CANCER SOCIETY, LOS ANGELES, CA; AND DR. CHARLES SMART, NATIONAL CANCER INSTITUTE, CHIEF, EARLY DETECTION BRANCH, U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

Ms. STACK. Can you hear me? Yes. Great.

Mr. Chairman and Members of the Committee, I'm extremely pleased to be here today to discuss Cancer Detection and Prevention in Women.

My name is Elizabeth Stack, and I'm an actress from Woodland Hills, California. I appear before you today on behalf of the American Cancer Society, ACS, the largest voluntary health agency in the world, comprised of 2.5 million Americans united to conquer cancer through balanced progams of research, education, patient service and rehabilitation. In 1988 the ACS is observing its 75th Anniversary. I think that's incredible.

And Senator Hatch, I'd like to take this opportunity to thank you for your courageous leadership on health issues for all Americans, particularly women. Thank you very much. You have been in the vanguard of our elected officials in Washington who fight every day to see to it that health care is available to each and everyone one of us.

Senator HATCH. Thank you.

Ms. STACK. In certain roles on television soap operas, made for T.V. movies, plays in London and New York, I have faced types of illnesses and tragedies that each one of us could experience. Within that none of these have even touched the kind of pain or tragedy that one feels when someone you love is dying of cancer or finds out that they do have cancer—your mother, your niece, your great aunt, your best friend. It's terrible. The disease is a terrible one.

In 1988 cancer will strike 985,000 American. Of these 490,000 will be women. This year 494,000 people will die of cancer, and almost half of those will be women. A staggering 174,000 cancer deaths in 1988 might be prevented by earlier diagnosis and prompt treatment.

Women must take responsibility for their own health care. This means exercising regularly, eating a balanced diet, and, of course, seeing a physician on a regular basis.

There are two types of cancer prevention, primary and secondary. Primary prevention refers to steps that might be taken to avoid those factors that might lead to the development of cancer. These include not smoking; avoiding prolonged exposure to the sun; reducing or eliminating the use of alcohol, especially if you smoke; and discussing cancer risks with your physician.

Secondary prevention refers to steps taken to diagnose a cancer as early as possible after it's been detected. For women three major detection tests are employed: Mammography to detect breast cancer, the Pap test and pelvic examination to detect cancers of the

reproductive organs, and screening tests to detect colon and rectal cancers.

Let's take a moment to review cancer deaths in women. In 1988 it is estimated that lung cancer will become the leading cause of cancer death among women, accounting for 20 percent of all cancer deaths. Now, the best way to prevent lung cancer is obviously never to smoke. I believe that continuing public education by groups like the American Cancer Society, the American Lung Association and others will and can help remind all Americans, young and old alike, that smoking can and really will kill.

In reference to this subject I would like to share with you a public service announcement with Larry Hagman and his niece. It's about smoking. David, take it away.

[Video.]

This is my niece Mary Devin. She is 11 years old. I asked her to help me warn people that smoking is bad for her. And she says she hates smoking so much, she didn't even want to talk about it. So I said fine. She can just sit here and not talk about it if she wanted to. "But, Mary, honey, now that you're here with a chance to influence millions of people, isn't there anything you want to tell the cigarette smokers of America?" "Don't." That's my niece. She'll talk your ear off if you let her.

[End of video.]

Ms. STACK. Thank you. Smoking rates, while generally declining, are increasing among teenage females. The bottom line is that we must convince people to never start smoking. Just don't smoke. That's the point.

The second leading cause of cancer death among women in 1988 will be breast cancer. For early detection the American Cancer Society recommends the monthly practice of breast self-examination, BSE. Women in consultation with their doctors should set up a regular schedule of examination by their physicians. And mammography, the most effective method of cancer detection, should be undertaken at regular intervals. I know that the small amount of time that I spend on complete breast examinations could and most probably will save my life. I strongly encourage all women to follow the ACS-recommended schedule for mammography for women over age 35.

Public education is the key to letting women know of the importance of early detection. Right now I'd like to share another public service announcement with you by a very special lady familiar to all of us Americans.

[Video.]

You should know this word "mammography." It's a fast and simple procedure that can detect breast cancer early while it's highly curable. Please call your doctor. The American Cancer Society urges self-examination, regular checkups and mammography for all women over 35. A mammogram can help save a woman's life.

[New voice.]

The American Cancer society commemorating 75 years of life.

[End of video.]

Ms. STACK. Mrs. Reagan's courage and candor during her illness and recovery did more for public awareness than we can ever imagine.

Now, the third leading cause of cancer death among women is colon and rectal cancer. Here again, regular testing by physicians

can increase survival rates, and public education should be used to encourage such testing.

The 4th leading cause of cancer death in 1988 among women will be cancer of the ovaries and uterus. Early detection through Pap tests and pelvic examinations can increase survival tests and rates.

Skin cancer this year will affect over 500,000 people. And it is, of course, highly curable if detected early. And I would like to share another public service announcement with you on this topic.

[Video.]

Premature wrinkles, saggy skin, skin cancer. Pay a few dollars for a bottle of sun screen. It's your choice. Fry now, pay later.

[End of video.]

Ms. STACK. Skin cancer can be easily prevented by avoiding the sun from between 10:00 a.m. and 3:00 p.m. when ultraviolet rays are the strongest, using sunscreen, and wearing protective clothing.

Mr. Chairman, good health care for women involves a number of factors. Awareness of any abnormal changes in our bodily functions or systems can lead to early detection and prevention of cancer.

Others must also be aware of the special health problems of women. Voluntary groups like the American Cancer Society must continue to educate America about cancer. Physicians and the insurance industry must make regular health care available and affordable and reasonable. And our elected officials must make the tough decisions in this time of fiscal constraints to spend whatever is necessary to see to it that all women are able to get the kind of health care they need.

Thank you very much. I will submit my full written statement for the record.

Senator HATCH. Thank you, Elizabeth. We really appreciate you taking the time to come up here, and we appreciate the voluntary work that you're doing with the American Cancer Society. It's really great to have you in Utah, and we hope you come back many, many times. Why don't you just stay there while Dr. Smart testifies.

[The prepared statement of Ms. Stack follows:]

TESTIMONY OF

ELIZABETH STACK

LOS ANGELES, CALIFORNIA

REPRESENTING THE

AMERICAN CANCER SOCIETY

REGARDING

CANCER DETECTION IN WOMEN AND OTHER HEALTH CONCERNS

BEFORE THE

COMMITTEE ON LABOR AND HUMAN RESOURCES

UNITED STATES SENATE

JUNE 3, 1988

FOR MORE INFORMATION PLEASE CONTACT:
JOHN H. MADIGAN, JR.
AMERICAN CANCER SOCIETY
202-546-4011

Mr. Chairman and Members of the Committee. I am pleased to be here today to discuss Cancer Detection and prevention in Women.

My name is Elizabeth Stack. I am an actress from Woodland Hills, California, and I appear before you today on behalf of the American Cancer Society (ACS), the largest voluntary health agency in the world, comprised of 2.5 million Americans united to conquer cancer through balanced programs of research, education, patient service and rehabilitation. In 1988 the ACS is observing its 75th anniversary of saving lives. Senator Hatch, I would like to take this opportunity to thank you for your courageous leadership on health issues for all Americans, particularly women. You have been in the vanguard of our elected officials in Washington who fight every day to see to it that health care is available to all.

In 1988, cancer will strike 985,000 Americans. Of these, 490,000 will be women. This year 494,000 people will die of cancer and almost half will be women. This is 1,350 people a day, about one every 64 seconds. Of every five deaths in the U.S., one is from cancer. A staggering 174,000 cancer deaths in 1988 might be prevented by earlier diagnosis and prompt treatment. Cancer is a large group of diseases characterized by the uncontrolled growth and spread of abnormal cells. If the spread is not controlled or checked, it results in death. However, many cancers can be cured if detected and treated promptly.

Mr. Chairman, there are two types of cancer prevention -- primary and secondary. Primary prevention refers to steps that might be taken to avoid those factors that might lead to the development of cancer. This includes not smoking; avoiding exposure to the sun between 10:00 a.m. and 3:00 p.m. when ultraviolet rays are the strongest; using protective clothing and sunscreens; reducing or eliminating the use of alcohol, especially if you smoke; discussing cancer risks with a physician prior to estrogen treatment to control menopausal symptoms; and monitoring diet by cutting down on total fat intake while eating more high fiber foods, foods rich in vitamins A and C, more cruciferous vegetables, and eating moderately of salt-cured, smoked and nitrite-cured foods.

Secondary prevention refers to steps taken to diagnose a cancer as early as possible after it has developed. For women, three major detection tests are employed: mammography for breast cancer, the Pap test for cancer of the uterine cervix, and a test to detect colon and rectal cancers.

For early detection of breast cancer, the American Cancer Society recommends the monthly practice of breast self-examination (BSE) by women 20 years and older. Examination of the breast by a physician should be done every three years from ages 20-40 and then every year. The ACS recommends a mammogram every year for asymptomatic women age 50 and over, and a baseline mammogram

between ages 35 and 39. Women 40 to 49 should have a mammogram ever 1-2 years, depending on physical and mammographic findings

For cervical cancer, women who are or have been sexually active, or have reached age 18 years, should have an annual Pap test and pelvic examination. After a woman has had three or more consecutive satisfactory normal annual examinations, the Pap test may be performed less frequently at the discretion of her physician.

The ACS recommends three procedures for the early detection of colon and rectal cancer in people without symptoms. The digital rectal examination, performed by a physician during an office visit, should be performed every year after the age of 40; the stool blood test is recommended every year after 50; and the proctosigmoidoscopy examination should be carried out every 3 to 5 years after the age or 50 following two annual exams with negative results.

Mr. Chairman, let's take a minute to review cancer deaths in women. Lung cancer is now the leading cause of cancer death among women, accounting for 20% of all cancer deaths. The best way to prevent lung cancer is to never smoke. I believe that continuing public education by groups like the American Cancer Society, the American Lung Association and others will help remind all Americans, young and old alike, that smoking can kill.

I would like to share with you a public service announcement with Larry Hagman and his niece about smoking.

Smoking rates, while generally declining, are increasing among teenage females. The bottom line is that we must convince people never to start smoking, period.

The second leading cause of cancer death among women is breast cancer. Earlier in my testimony, I discussed the ACS recommendations for early detection of this disease. Regular breast examinations and mammograms for those women over 50 is the best course of action. Again, public education is the key to letting women know of the importance of early detection. I would like to share another public service announcement with you done by someone familiar to all Americans. Mrs. Reagan's courage and candor during her illness and recovery did more for public awareness than we can ever imagine.

The third leading cause of cancer death among women is colon and rectal cancer. Again, public education and regular testing by physicians can increase survival rates.
The fourth leading cause of cancer death among women is cancer of the ovaries and the uterus. Periodic thorough pelvic examinations are important for women over 40 to detect ovarian cancer early. Pap tests are the key for detecting cervical cancer.

Mr. Chairman, good health care for women involves a number of factors. First and foremost, women must take responsibility for the quality of their health. This includes eating a balanced diet, avoiding obesity and getting regular examinations by their physicians. It involves self-awareness, in order to detect any abnormal changes in their bodily functions or systems.

Secondly, others must be made aware of the special health problems of women. Voluntary groups like the American Cancer Society must continue to educate America about cancer. Physicians and the insurance industry must make regular health care available at an affordable and reasonable price. And our elected officials must make the tough decisions in this time of fiscal constraints to spend whatever is necessary to see to it that all women are able to get the kind of health care they need.

Thank you. I would be glad to answer any questions you might have.

Senator HATCH. We'll introduce at this time Dr. Charles R. Smart, M.D., who is Chief of the Early Detection Branch of the Division—the Early Detection Branch Division of the Cancer Prevention and Control Center of the National Cancer Institute, the National Institutes of Health of the U.S. Department of Health and Human Services.

I want you to know how proud we are to have him with us here today because he heads the Community Oncology Department or Program of the National Cancer Institute for the National Institutes of Health. He is going to discuss this morning the need for early detection including Pap smears, breast examinations, skin cancers, lung cancer, etc. I believe, Doctor, you have a slide presentation as well.

Dr. SMART. Yes, I do.

Senator HATCH. Pull that microphone over a little bit, Charles. We're very interested in what you have to say.

Dr. SMART. Thank you very much. Senator Hatch and Members of the Committee, I'm Charles Smart, M.D. in charge of the Early Detection Branch. And I would like to talk to you just a moment about cancer detection in women.

Seems to me first of all we need to understand the problem. The first slide shows some working guidelines that were developed last September by the National Cancer Institute. Up until that time the only thing we had—up until that time the only thing we had was the ability to make recommendations on mammography and on Pap smears. And we felt that there were certainly more recommendations that could be made than these two simple things.

And so if you were to look at this handout on Table No. 1, it shows U.S. Cancer Mortality in Women. And it shows breast cancer. This was in 1985. The estimates are that lung cancer will pass breast cancer. But in 1985 as far as at that time breast cancer was number one; lung cancer was number two; colorectal cancer; and then ovary, pancreas, leukemia and so forth.

If we were to look at Utah, we actually see that the order is very different in Utah as far as cancer mortality in women. Going first of all digestive tract, breast, genital, then lung, and so forth.

There is a comparison in Table No. 3 which shows the U.S. vs. Utah. And it simply shows particularly in lung cancer we've got about one-third as much lung cancer in Utah as there is in the U.S. in general.

The fourth table simply shows that the incidents of cancer goes up directly with age. And beginning at the age of 35 or 40, why, it takes a very sharp curve and goes up rather remarkably.

I'd like now to show you the rest of the recommendations which I think are rather remarkable only because they bring us in accord with the Cancer Society. And we've been very happy to see this happen. The next slide, please.

These were called Working Guidelines. These working guidelines were based upon the best statistical and clinical information currently available, not always on a randomized trial with mortality as an end point, subject to change with new scientific information, and they were supported by the relevant medical organizations. The fact is we've got about 80 percent of medical organizations

presently that are endorsing these. And we expect that it will be higher by the end of summer. Next slide, please.

These are to encourage physicians in utilizing the principles of good medical care to facilitate early cancer detection: A complete physical examination, examination of the skin, oral cavity, lymph nodes, breasts, cervix, pelvic area, and so forth. Patients with suspicious signs or symptoms, of course, should have usual diagnostic tests. Next slide.

It was also to encourage patients to be responsible for their own health in as much as possible—abstinence from smoking; avoidance of severe sunburning; avoidance of dietary and other factors that predispose to cancer; to be encouraged in instruction in periodic self-examination of the skin, of the breast, and in men, of course, of the testicles. Next slide, please.

In breast cancer which is the number one concern, I believe, of women the physician should encourage female patients in doing monthly self breast examinations. They should be encouraged to do clinical—doctors should be encouraged to do clinical examination in all their female patients in whom they're doing a periodic health examination.

And beginning at age 40 a mammogram should be encouraged every one to two years until the age of 50, after which time they should become annual. In women with a personal history of breast cancer a mammogram should be encouraged annually. Next slide, please.

Colorectal cancer. Colorectal cancer, as I said, if you put colon and rectum and the digestive diseases together, they become number one in Utah. And they're among the one, two and three in the United States. We believe in the control of colorectal cancer. A rectal examination is part of the periodic health examination that ought to be encouraged. Frequently it's omitted. And I think that it's really important to stress that it be included as part of the health examination, particularly after the age of 40.

At the age of 50 an annual fecal blood testing and sigmoidoscopy should be done every three to five years. This actually will detect cancers—where we're detecting about one-third of colorectal cancers early, this would detect about 70 or 80 percent early. And that physicians should identify for special surveillance high risk patients, those with a strong family history of colon cancer, or with a personal history of polyps, colon cancer and inflammatory bowel disease. Next slide, please.

In the case of uterine cancer we and the American Cancer Society along with other organizations came up with the united proposal which is this: That all women who are or have been sexually active or have reached the age of 18 have an annual Pap test and pelvic examination. After a woman has had three or more consecutive, satisfactory, normal examinations, the Pap test may be performed less frequently at the discretion of her physician. Next slide.

Skin cancer. In Utah skin cancer makes up more cancer than all other cancers put together. But we ordinarily don't follow them closely. We don't count them. We don't follow them until death as we do with the other major cancers. And therefore, they sometimes get left out. But it is extremely important. And right now one particular variety of skin cancer, melanomas, have been increasing

more rapidly than any other cancer, and they are the ones that cause most of the deaths in skin cancer.

And the recommendation is that all individuals should be encouraged to examine their skin thoroughly on a regular basis, that the primary care physician should be encouraged to examine the skin as part of the periodic health examination. Sometimes we look at the patient, but we don't look at the skin, and it's important for us to examine the skin thoroughly. And that further public and private education should be promoted on early detection of skin cancers, and in particular, malignant melanoma. Next slide.

The oral cavity is also easily examined. One can look in, palpate the tongue, floor of the mouth, salivary glands, lymph nodes of the neck as part of the periodic health examination. And special attention should be given to those who use tobacco or alcohol. Those are two predisposing causes which are present in nearly 80 to 90 percent of all patients with oral cancer.

Senator Hatch, we believe that the use of these guidelines will greatly enhance the early detection of cancer and significantly reduce the deaths from cancer in the future.

Thank you very much for allowing me to present this to you.

[The prepared statement of Dr. Smart follows:]

STATEMENT OF CHARLES R. SMART, M.D.

CHIEF, EARLY DETECTION BRANCH

DIVISION OF CANCER PREVENTION AND CONTROL

NATIONAL CANCER INSTITUTE

NATIONAL INSTITUTES OF HEALTH

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

BEFORE

THE

SENATE COMMITTEE ON LABOR AND HUMAN RESOURCES

JUNE 3, 1988

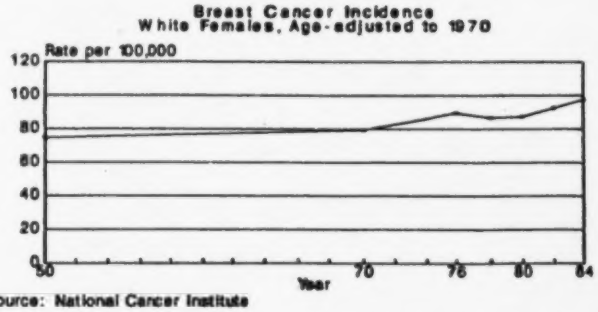
Mr. Chairman and Members of the Committee:

I am Charles R. Smart, M.D., Chief of the Early Detection Branch in the Division of Cancer Prevention and Control of the National Cancer Institute. My branch is responsible for identifying, evaluating, and encouraging the implementation of effective early cancer detection procedures in the United States.

It is a privilege for me to be here today to discuss the early detection of breast cancer. Breast cancer is the leading cancer in women, with an estimated 130,000 new cases and 41,000 deaths annually. It is responsible for more new cases of cancer among women than any other cancer. It is also the leading cause of cancer death among American women. One of every 10 women in the United States is expected to have breast cancer some time in her life.

Breast cancer incidence has been increasing at the rate of one percent per year since 1950 (Table I). While the reason for the rate increase is not entirely clear, the number of women who will be diagnosed with breast cancer in their lifetime is greater than even before because women are living longer. As

Table I

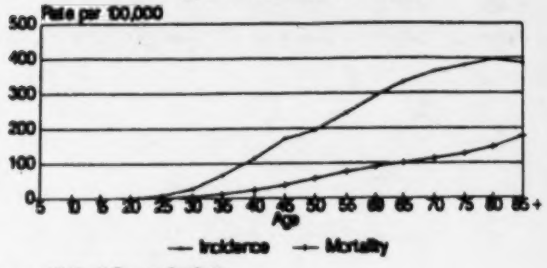


Source: National Cancer Institute

depicted in Table II, as women get older, breast cancer increases substantially. In this regard the number of new cases increases from 150 per 100,000 at age 50 to 170 per 100,000 at age 70.

Table II

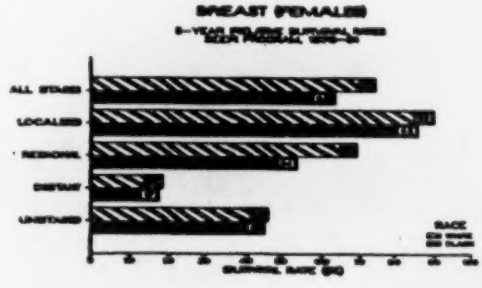
Breast Cancer Incidence and Mortality During 1981-1985, Females by Age



Source: National Cancer Institute

Detection of breast cancer at an early stage strongly influences the success of treatment. Minimal breast cancers are highly curable when treated by surgery (including lumpectomy) combined when necessary with adjunctive therapies (e.g. radiation and/or chemotherapy). Current data from the National Cancer Institute's Surveillance, Epidemiology and End Results Program (the SEER Program) for the period 1979 to 1984 show that, of newly diagnosed women, 49 percent had localized disease at diagnosis, 41 percent had regional disease, 7 percent had distant (or metastatic disease) and 3 percent had no record of the stage of disease. As shown in Table III the five-year relative survival rates for white and black females detected in these stages were: localized--90 percent for whites, 86 percent for blacks; regional disease--69 percent for whites, 54 percent

Table III



for blacks; for distant disease--18 percent for whites and 17 percent for blacks and for cases in which the stage was not recorded, 46 and 45 percent for whites and blacks respectively.

Mammography together with physical examination is the most effective method for detecting early stage breast cancer. Such early detection of breast cancer requires screening examinations in asymptomatic women--that is exams before the patient or the physician is able to perceive an abnormality, such as a lump. Minimal breast cancers often are included as a subgroup of the localized stage. They made up 9 percent of all cases diagnosed from 1973 to 1984. Minimal breast cancer has only been recognized as a special category in the past 12 years, with the widespread use of mammography. This group has been defined as including all non-invasive or in-situ cancers plus invasive cancer under one centimeter in diameter. Ordinarily, minimal cancers cannot be discovered by the woman or her physician because of their small size. There are most frequently detected by mammography.

In 1963, Shapiro and Strax organized an breast cancer detection trial in the Health Insurance Plan of Greater New York (HIP). Approximately 62,000 women 40 to 64 years of age were randomized into a study group to be offered 4 yearly mammograms with concurrent physical breast examinations and a control group that were to continue usual medical care. At six years from entry into the study there was evidence of a 30 percent reduction in mortality from breast cancer in the women over 50 years of age who were offered screening, as compared to the control group. Now at

18 years followup, there is an equal benefit for those in the 40-49 hear age group. Two other studies, one from Sweden and one from the Netherlands, have shown similar, if not even greater benefit in women over 50 years of age.

In 1973, the National Cancer Institute and the American Cancer Society co-sponsored a Breast Cancer Detection Demonstration Project (BCDDP). Twenty-nine breast cancer detection centers across the country enrolled more than 280,000 women 35-74 years of age. The women were offered five yearly mammograms plus a breast examination by a physician or nurse. Of the 3,548 breast cancers detected as a result of the screening project, one third were minimal cancers and eighty percent were classified as localized disease, having no lymph node involvement. As I noted, in the general population only 49 percent of cases are detected at the localized stage. Survival rates for all the screening detected cancers were exceptional, 91 percent at five years and 81 percent at 10 years, similar to that seen in the SEER program for localized cancer.

Mammography as a technology has improved substantially between the 1960's HIP study and the 1970's BCDDP in its ability to detect cancer. In women 40-49 years of age about 39 percent of all cancers were detected in the HIP study when mammography alone and mammography plus physical examination were used. In the BCDDP study mammography detection increased to 90 percent, in women 40-49 years of age and in women over 50, detection increased from 60 to over 90 percent. This means that mammography as a detection technology is as accurate for women age 40-49 as for 50 and

over. In addition, the likelihood of a cancer being detected at the minimal regional stage has increased from 9 to 42.4 percent. It should also be noted that, since the 1970's there has been a 6-to-10-fold decrease in radiation exposure. At present, the radiation risk is considered to be negligible in comparison to the benefits for all women 40 years of age and older.

In conclusion, Mr. Chairman and members of the Committee;

1. Breast cancer continues to be a major concern problem for American Women.

2. Mammography and physical examination in asymptomatic women are the most effective method of early detection.

3. With the improvements which have occurred in mammography, the risks from radiation are now negligible.

4. If modern mammography and physical examination were applied broadly in the United States to the population of women over 40, there is good reason to believe that mortality from breast cancer would decrease by 30 to 40 percent.

Thank you very much for allowing me to testify, and I would be glad to answer any questions.

Senator HATCH. Thank you. We appreciate the really clear-cut way you've explained this, and we appreciate you coming out to your homestead. We also appreciate all the work you did while you were at L.D.S. Hospital.

I'd like to ask Ms. Stack some questions. First, I want to thank you for your very insightful testimony and for representing the American Cancer Society. It's really a pleasure to learn about the activities of the American Cancer Society.

As a matter of fact I've been reviewing many of the wonderful educational materials that the Society has made available to us today. For example, there's a laminated guide that provides women instructions on how to do breast self-examinations. It's waterproof so it can hang in the shower. It slips on the shower nozzle, and it shows you how to make the examination. It's a very, very helpful chart. They are available on the table in the back, and I hope that folks will pick one up. Let's make sure we have a lot for our home state of Utah. We're going to try to get this all over the country. These are wonderful.

Yes, ma'am.

UNIDENTIFIED SPEAKER. Senator Hatch, that was developed by Intermountain Health Care as a public service for the area. They are available in this state through the Women's Centers at IHC.

Senator HATCH. That's great. And this is something that seems to me will make a lot of difference. It ought to be pushed all over the country, because if you'll hang it in the shower, you'll know exactly what to do. It's just a very good thing, and I want to compliment you for it.

There's another brochure which answers questions on skin cancer. You can pick all of those up in the back. It was produced by the American Cancer Society. There's also one on breast cancer detection awareness, and, in fact, some colorectal cancer. I think you'll want to look at those and perhaps get a copy of them. I think you'll find those to be very informative.

These are all informative materials. How can the American public get such information? Is there some clearing house or national clearing house or way to do so?

Ms. STACK. Of course, people can contact the local American Cancer Society. There's a society in all fifty states, in every neighborhood, and right across the country. In fact, in Utah the Society can be reached at 610 East South Temple, and right here in Salt Lake City at 322-0431. And audience members can find this book at the back of the room. And on the back it has all the numbers and addresses of all the different divisions around the country.

Senator HATCH. Do you also provide resource and referral information for people who want to check on warning signs of cancer?

Ms. STACK. Oh, yes. We have numerous services, and we also have numerous programs. One of them is called Reach to Recovery, and that's a very special program in which breast cancer volunteers counsel breast cancer patients. It's very, very special.

We also have a program where volunteers drive patients to their medical treatments.

Another program we have is called the loan closet. And this is where families and parents can borrow hospital beds, wheelchairs.

For example, if someone has lost their hair due to chemotherapy, they can borrow a wig.

What I think is most important for all of this is that these programs are at no expense to the U.S. taxpayer. In every single one of these programs our money was raised by our volunteers.

Senator HATCH. That's great. There are proposals in the Congress to have Medicare pay for certain types of preventive cancer screening tests. We'll have to see what happens there. Are you aware of any proposals, and can you tell us the American Cancer Society's view of such proposals?

Ms. STACK. Yes, I am, Senator. As a matter of fact, yesterday the House of Representatives approved a catastrophic health insurance bill. And among the many provisions, mammography will now be covered for and made available by Medicare, which I think is incredible. The ACS, of course, supports this because it's much easier to detect and prevent cancer than to treat those who are dying of cancer.

And as a matter of fact, the American Cancer Society would urge the Congress to go one step further in all kinds of cancer prevention detection tests: Pap tests, colorectal checks, etc. And I know later this morning we're going to be hearing from others who will be discussing other health problems in the nation.

And the Cancer Society believes that Congress must start dealing with the 55 million Americans who don't have access to health insurance or adequate care.

Senator HATCH. We do have a cancer screening clinic in St. George that is really becoming world renowned because of the way it's going to check on the people who were downwind of the atmospheric tests in the Fifties and Sixties. It also is a facility where many of these tests can be obtained. We want people in Utah to be aware of that.

I just have one personal question for you, Ms. Stack. May I ask you why you've elected to volunteer your time to the American Cancer Society?

Ms. STACK. I'm a member right now of a wonderful group called Celebrities Against Cancer. I believe every disease is a terrible thing. Cancer has touched my family. My best friend has sadly—when she was 18 had cancer of the thyroid. She had five different forms. She is in remission now, but the fear that she has and the pain that she's gone through is devastating. My great aunt, my mother was at her bedside washing her hair as she was dying.

It's like if God willing we can prevent this in any way, I want to be a part of doing that. And I want to urge as many people as possible in doing their part in protecting all of us. We never know. We can try to be as healthy as possible, to find out as much as we possibly can about preventive tests and everything. It's essential for us all to have a better life. I want to be a part of helping as many people as I can.

Senator HATCH. Thank you. I want to thank you for your wonderful testimony. Say hello to your dad. It's been a while since I've seen him. We want to thank people like you who take the time out of your busy schedules and make the effort to participate in these types of activities that really help all of us. I just want to thank you, for coming up here to Utah and voluntarily doing this——

Ms. STACK. I ski. I'll be back.

Senator HATCH. We expect to have you back. I also want to thank John Madigan, who is the Government Affairs Expert and Director for the American Cancer Society, for his continued effort to work with the Congress on these issues. We appreciate both of you being here.

I want to sit and listen to Dr. Smart. I know that he's enjoyed sitting beside you here today. [Laughter.]

Ms. STACK. I've enjoyed it too.

Senator HATCH. He's one of the great people.

I want to ask a couple of questions to you, Dr. Smart. Thank you for your presentation. I think it was very lucid and something that all of us can understand. I want to begin by commending you for your leadership not only at the National Cancer Institute, but here in Utah. You've made a lot of difference to us. I know that the Utah Cancer Registry blossomed because of you, and it provides valuable information to thousands of people here in our state, so I want to thank you for your continued leadership.

Dr. Smart, what are some of the obstacles that prevent women from doing breast examinations and then having mammograms?

Dr. SMART. I believe that one of the more important things is that there has been a lot of disagreement among medical organizations as far as advocating as a unit the importance of it. I think the Cancer Society has done a magnificent job. Even in all the literature at the National Cancer Institute we've been heavy advocates of it. But many have not been advocates of it as much, so we've been working to see if we couldn't get the medical community to speak as a voice backing these recommendations. We think that would be very helpful.

I think—in addition I think that there are some women who really still don't really know about self breast examination.

Senator HATCH. They may be afraid of costs. They may be afraid of exposure to radiation. They may be afraid, period.

Dr. SMART. As far as radiation is concerned I think it's important to really recognize one thing, and that is mammography has really changed dramatically.

Back in 1976 there was a big concern about the amount of radiation women were getting with mammography. Right now mammography has changed so much that—well, take for instance in the 1960's only 36 percent of women that were younger, under 50, were able to be detected by mammography. It's now—in fact, in the 1970's it was 90 percent. And in the 1960's it was only 60 percent of the women that could be detected by mammography. And now it's over 90 percent, 92 percent. So right now we can detect with mammography just as many early cases in younger women as we can in older women.

But the amount of radiation has gone down dramatically. In fact, right now it's even down to—average of about three-tenths of a rad per examination. At that time, in the early times, it was 7 or 8 rads. And so the amount of radiation was perhaps of concern back in the early 1960's and in the 1970's. But right now it's down to the point where it's really negligible.

Senator HATCH. You almost get more than that from your television set.

Dr. SMART. That's right. Or flying from Washington to here.

Senator HATCH. I wish you hadn't said that.

[Laughter.]

Dr. SMART. The fact is—the exciting part is that say in the HIP Study of the 1960's which was a demonstration project of what one might do with early detection of mammography, only 8 percent were what we called minimal cancers.

In the demonstration project of the American Cancer Society and the National Cancer Institute in the 1970's that went up to 32 percent. And as we look at the results of this 280,000 women that were screened as a demonstration project, we're seeing 80 percent ten year survival rates.

It's almost to the point where we can—as you stated earlier, we're getting up to the 80 or 90 percent survival rates in breast cancer. And we can virtually do away with nearly all breast cancers if they would follow these recommendations of the National Cancer Institute and the American Cancer Society.

And I think the fear of radiation has been a big deterrent. I think doctors have also been caught up in that. And I think we've got to do a job as far as professional education, and we're working on that.

Senator HATCH. What about costs? Aren't women a little afraid of costs?

Dr. SMART. I think costs are important for them. And I think that the American Cancer Society in particular have been pressing for screening mammography $50.00 or under. And I think the present thing that's in Congress put a cap on it at about $35.00. And I think costs have been a big problem, and they are a big concern.

Senator HATCH. That's a small price to pay on an annual basis to be at least 92 percent sure that things are all right.

Dr. SMART. That's right. But it used to be that a mammography would cost you $100.00 or $200.00. So great strides have really been made in costs.

Senator HATCH. That's great. Now, Doctor, we have spent billions of dollars over the past decade on cancer research programs funded through the National Cancer Institute. Has this money been well spent? Have we gained a lot from these types of ethics?

Dr. SMART. I think that if you ignore lung cancer, which is still going up, the fact is for the first time in 1985, 1986 and 1987 in men we saw a decrease in lung cancer incidents, particularly in white men. But in 1986 also in black men there was a decrease, meaning that—well, take for instance smoking. In 1960 there was 52 percent of men smoked. Right now it's down to 32 percent. And it's similar—and with that decrease we're beginning to see a decrease in incidents.

And right now we're seeing a plateauing of the mortality rate. And over the next few years we would expect to see a decrease. The trouble with it is there's still a great many people that are smoking. Still one-third of men are smoking. And in women we haven't made nearly as much inroads on smoking in women as we would like to.

So the answer is if you ignored lung cancer, there has been some really significant strides in many different cancers with a 13 per-

cent overall decrease in mortality ratings over the last 20 years due to better treatment, early detection.

But actually with early detection I think we can make much greater strides. We're heading for—we want to see if we can get a 50 percent decrease in mortality rating by the year 2000, and it is possible.

Senator HATCH. That would be terrific. I remember just a few years back when I think almost everybody saw some child die from leukemia—almost all of them died, and many never knew they had leukemia.

I went down to M.D. Anderson Clinic, among others around the country, and over the last 20 years they've gotten to the point where they've almost stamped it out. It's just been amazing. I mean almost everybody died, and then they got to where almost 50 percent they were able to save. Now it's a very high percentage of those they are able to save.

A lot of that comes from the National Cancer Institute and the funds that it provides and the help that it gives to clinics like M.D. Anderson, and, of course, L.D.S. here, and others all over the county. So I want to commend you for that.

It's my understanding that lung cancer has recently overcome breast cancer as the leading cause of death from cancer among women. Now, is this primarily because more women are smoking today, or have we done a better job to prevent and heal breast cancer than lung cancer?

Dr. SMART. No, I don't think there's been a decrease in breast cancer in particular. There's been a slight decrease in the mortality rate for breast cancer in women under 50. But indeed it is due to the fact that women started smoking about 20 years ago at a much greater rate, and it's now just catching up with them.

In fact, we're now seeing true equality between men and women. They're going to have as many breast cancers in women as there are in men given another 10 or 15 years unless there is a change in trends. So I would say that it's because of the increasing rate of lung cancer in women related to the delay or the fact that they didn't used to smoke as much as they do now.

Senator HATCH. And, of course, I see all these ads dedicated to encouraging women to smoke as the "in" thing to do, so a lot more women are smoking.

Dr. SMART. That's correct.

Senator HATCH. That is interesting. I learned from the Utah Department of Health that they are providing cancer screening clinics around the state. So from your experience in Utah do you feel that we are providing sufficient services in Utah where women can have access with regard to cancer?

Dr. SMART. Certainly. There are the screening clinics which are going on regularly which are being carried out by the State Health Department. Previously it was done through the Cancer Society. And I feel that those services are available.

Senator HATCH. Thank you. I want to thank both of you for your excellent testimony and the help that you've brought to this hearing today. This helps me because I have to go back and fight as hard as I can for some of these health programs.

We have colleges back there that come up with bombastic programs that sound wonderful, but there's not enough money in the world to pay for them. Some of us have got to try to make our moneys go as far as they can to really solve these problems. We also have to authorize these bills that really work. It's testimony like this that gives us ammunition and helps us go back and do what really needs to be done.

I want to thank both of you. You've both done a great service here.

Dr. SMART. Senator Hatch, we both appreciate being able to testify.

Senator HATCH. Thank you. Good to have both of you here. Thank you.

Our second panel will discuss another important health care issue—long-term care. America is experiencing a longevity revolution as 5,200 Americans each day join the ranks of our senior citizens. We are enjoying long and productive life styles, and I might say long and productive life spans as well. While the prospect for longer life spans is good news, it also begets new issues. Our greatest concern is the health care needs for our citizens, and, of course, of our senior citizens.

Long-term care is often associated with the needs of the elderly, but let's not forget that many of our children are in need of long-term care. Let me give you an example. We have an 8 year old girl right now in Salt Lake City named Jamie Delgado. She lives in west Salt Lake City. She has cerebral palsy.

When she was institutionalized, her physical therapy prognosis was very, very negative. But with physical therapy provided in the home during the last 18 months Jamie has shown amazing progress. With two additional surgeries and therapy this girl, who nobody ever thought would walk, is now walking. But she will need extended care.

She will never be able to resolve these problems if we let her down. We must never let Jamie or young people like her down, especially when we have the means at our disposal to try to resolve these problems. Home health care is one of the ways we can do it.

Other examples can be cited. I think, we've all heard the story about an elderly family member with a lingering illness who was forced to sell his or her home to pay off the mounting hospital, physician and prescription drug debt not covered by federal or private insurance. Examples of financial ruin caused by catastrophic health care costs, can be found almost anywhere.

Long-term health care is a problem that falls heaviest, it seems to me, on women in our society for one primary reason—women generally outlive men. They are called on to care for their husbands, and then eventually they need help for themselves, So we need to address this very serious problems.

But the fundamental question that Congress has to decide—and decide fast—is what kind of care and assistance can be offered in a deficit ridden era, and in what type of setting should that care be provided. I have advocated expanding home health care services as a primary solution, but I do look forward to the testimony of two experts here today who will describe our current need for such services. We will hear the provider perspective from Shauna

O'Neil, Director of Salt Lake County Aging Services, as well as from Mrs. Marian Lewis who is a caregiver to her ailing husband and who recently has required help for herself.

I think I'd like to call Ms. O'Neil and Mrs. Lewis to the witness table at this time if we can. Now, Ms. O'Neil why don't we begin with you. We'll take your testimony at this time, and then we'll go to Mrs. Lewis.

STATEMENT OF SHAUNA O'NEIL, DIRECTOR OF SALT LAKE COUNTY AGING SERVICES, SALT LAKE CITY, UT; AND MARIAN LEWIS, SALT LAKE CITY, UT

Ms. O'NEIL. Good morning, Senator Hatch.

Senator HATCH. Good morning.

Ms. O'NEIL. It's a pleasure to be here today. And as, I guess, the representative of Salt Lake County I take particular pleasure in welcoming you to our new County Government Center.

Senator HATCH. We'd like to thank the County for making this available to us. It's really a wonderful place.

Ms. O'NEIL. It's a privilege to have you and we enjoy having guests come and visit us here. And it's particularly a pleasure to have a hearing on this very important topic in Salt Lake City. I have given you previously a written statement. I'd appreciate it if that could be just added as part of the record.

Senator HATCH. Without objection we'll place it as part of the record.

Ms. O'NEIL. Thank you. Long-term care today means both live-in home care, but also a wide range of services which are provided in the home by an amazingly wide variety of personnel. We have doctors, nurses, other traditional medical practitioners, through home health aids, homemakers, delivery of Meals on Wheels, transportation drivers, as well as technicians who do very complex types of services such as kidney dialysis which only a few years ago could not even be provided in hospitals. This very wide range of services is the continuum of long-term care—those services which are provided in the home constitute community based long-term care.

As you mentioned, persons of all ages need long-term care, need home health care. The issues and problems are very much the same regardless of the age of the patient or the caregiver. Almost one-third of persons in this country who need assistance with personal care are under the age of 65. So as you pointed out, it is much greater a need for the younger population than I think we generally realize. But the focus of long-term care must and will continue to be the elderly and those who love and care for them.

Utah as well as America is aging, and the number of the very old is expanding at the greatest rate of any expansion of our population. The economy of Utah—we're the youngest state, but we're also the state which has the 6th fastest growing aging population of any state in the county. And it's that latter part of our economy that we do not understand nor recognize. This means that we can not ignore the need for services to meet the needs of the elderly. For with advancing years the need for assistance grows significantly. Almost three times more people over the age of 85 need home health care and other services than persons under the age of 65.

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As you pointed out also, it's very appropriate to talk about the need for home health care and long-term care as a women's issue. Women are not only the people who are cared for, they are also the people who provide the care for their loved ones. They are the daughters, the daughters-in-law, and the wives who care for the elderly. Also we must remember that women are most of the professionals who care for the elderly in their homes as a profession and as a job.

Caregiving is often a 24 hour a day job. The demands and stress under which the caregiver exists are enormous. And we'll hear from Mrs. Lewis graphically describe that in a few minutes. Often we find the caregiver in far more immediate danger of serious health problems than is the person to whom care is being provided. It is really not overly dramatic to say that we've seen people die from the strain and stress of caregiving, and the person for whom they were providing the care lives five, six, seven years longer than the caregiver did.

For more than ten years Salt Lake County Aging Services has managed a program designed to assist persons over the age of 18 to stay in their homes rather than enter institutions. We called it The Alternatives Program. We feel it is far better to provide the caregiver with limited assistance so the situation in the home can remain in intact, than it is for the family to become exhausted and decide that they can no longer continue. Through The Alternatives Program home health care, Meals on Wheels, transportation and significant other services are provided to provide relieve for the caregiver.

Our experience is that each element of the long-term care system is very badly needed. Nursing homes must be available when the person's condition deteriorates to a point that care can no longer be given in the home. And nursing homes are now being used increasingly as intermediate locations where persons go upon release from a hospital until they're able to return home.

Also, home health services which are provided by licensed or certified Home Health Agencies often replicate services provided in institutions or in hospitals. But because they're provided in the home where family members can provide assistance, those services that are given can be limited to those which the family has neither the capability nor the energy to provide.

Supportive services, such as Meals on Wheels, resident care, transportation availability, are also key factors in keeping someone at home because often the provision of a meal, or assistance with bathing or other simple tasks is what that person needs in order to stay home.

I feel that case management is the glue which holds this system of services together. A case manager assesses a patient's condition, orders services, and then most importantly is available to watch and make sure that the services provided are adequate and to step in and provide assistance or more services if a situation deteriorates.

It's important that the case manager be from an agency which is disinterested, which does not have a stake in the services which are ordered. This is to ensure that a minimum number of the most cost

effective services are ordered, and that the quality of the services provided is monitored sternly.

I have seen community based long-term care. And this combination of different services provided by different agencies perform miracles for very elderly, very fragile persons.

I have been a director of an area agency for ten years, and I have become increasingly convinced that it's the height of bad public policy for us to do anything which jeopardizes the health the older persons. Older persons can't bounce back from an illness or a traumatic condition like younger persons can. And when they get very ill, their care becomes very expensive.

The public policy makers must recognize that we will be paying more public money to provide health care to the elderly persons. And I believe that the American public will support increased expenditures. Rolling Stone Magazine, hardly an advocate for elderly issues, published a poll of its readers on April 7th of this year. To "provide better/more affordable long-term care for the elderly" was the most often answer to the question, "Which one or two domestic goals would you say are most important for the next president to address?" This is an answer from people who are 18 to 40 years of age.

The real challenge is how to provide the assistance more cost effectively. We must provide effective low cost care in the home, but it must be readily available to those who need it.

Some additional observations. Policies which impact hospitals and nursing home services and utilization have a direct and forceful impact on the need of services in the community. Payment by Medicare on the basis of DRG's has increased the need for community based health and support care enormously. But the money to provide that care has not been provided.

Services in the community must also be comprehensive and must address the full range of critical needs of the elderly. Home health care as well as supportive services are both critically important.

Elderly persons and their families must remain involved and must remain responsible for caring for themselves and for their loved ones. Too much assistance is damaging for it builds dependency. It is critical that older persons remain as independent as possible. We need to focus on the development of low cost services and support the families so they remain involved.

The reimbursement mechanism which we presently have, not the needs of the client or the family, has driven the design of the system. Policies which artificially limit the number of visits which can be made, which terminate care when a condition is stabilized, or forces other funding sources to subsidize government supported care inhibit the provision of badly needed care to very ill persons and often encourage institutionalization which is far more expensive.

The payment mechanism is too complex, frail and sophisticated for low income people who become discouraged, and needed help is not provided.

Expanded funding and additional financial resources need to be developed. There are simply not enough services available. Government funding must be increased at the federal, state and local levels. Charitable resources must be expanded. And private long-

term care insurance must include payment for both in-home and supportive as well as nursing home care.

Community based long-term care provides care that is needed in the location in which the patient has the best chance of thriving, at home. It's where people want to be. It's where their families want them to be. Simple help can do so much in the lives of these patients.

Thanks to the efforts and leadership of farsighted policy leaders such as yourself, Senator Hatch, we are gradually building a system which does protect and serve those to whom we owe so much—our parents and our grandparents. And thank you very much for your help through these last years. Please continue to help us. Your efforts have been significant, and as with the expansion of the Senior Companion Program and the passage of the Health Care in the Home Act successes are beginning to be seen. But we have not yet arrived at the end of our journey.

[The prepared statement of Ms. O'Neil follows:]

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SHAUNA O'NEIL
DIRECTOR

STATEMENT ON
LONG TERM CARE

BY

SHAUNA O'NEIL, DIRECTOR
SALT LAKE COUNTY AGING SERVICES

BEFORE THE
SENATE COMMITTEE ON LABOR AND HUMAN RESOURCES

SENATOR ORRIN G. HATCH, PRESIDING
SALT LAKE CITY, UTAH
JUNE 3, 1988

Good morning, Senator Hatch. I am Shauna O'Neil, Director of Salt Lake County Aging Services and Secretary-Treasurer of the Utah Association of Area Agencies on Aging. In addition to our agency's direct experience with the need for long term care, as President of the National Association of Area Agencies for two years, I had the opportunity to compare the development of the long term care system throughout the nation. Also, the Commission on Legal Problems of the Elderly of the American Bar Association, on which I serve, has concentrated for the past two years on issues relating to assuring the quality of home health care.

I am very pleased to be here with you today to discuss the needs for long term care in this nation. This is a complex and controversial topic, a subject upon which both practical experience and public policy are still in the formative stages. Even the definition is in flux. Long term care originally meant nursing home care. But no more. It has evolved to also encompass an extremely wide range of services which are provided in the home by a variety of personnel which range from doctors and other traditional medical practitioners, through home health aides, homemakers, meals on wheels delivery persons and transportation drivers, to technicians who conduct kidney dialysis and other highly technologically sophisticated treatments. This is the continuum of long term care - those services provided in the home constitute community based long term care.

Although most of the focus of my experience and remarks are aimed at services for the elderly, the reality is that persons of all ages need long term care. The issues and problems are very much the same regardless of the age of the

patient or the caregiver. It is estimated that about 8 million persons needed assistance with personal care in 1985 - about 5.2 million of them were over 65 years of age, but almost 3 million were younger.

But the focus of our concern for long term care must be the elderly and those who love and care for them. We have long recognized that America is aging - and that the number of the very old is expanding at the fastest rate of all. In Utah, however, we have felt that we are different - that our problems are not the aging of the state's population, but the young. We must now recognize that we are not immune to the aging of the nation's population. For the dichotomy of our state is that while we are almost the youngest state in the nation, we are also the sixth fastest aging state in the country. It is the oldest of the old - those over 75 years - whose numbers are growing the fastest. Between now and 2000, the number of young persons in Salt Lake County is expected to grow 16%; the number of persons over 75 years is expected to grow 61%.

This has great implications for the development of services and programs to meet the needs of the elderly, for with advancing years, the need for assistance grows significantly. For example, the need of assistance with activities of daily living increases dramatically with age. Only 2.6% of persons age 65-74 need assistance with personal care but 31.6% of those over 85 need such aid. It is as these physical limitations develop that the need for the continuum of long term care services becomes important.

It is appropriate that this issue be discussed today, for long term care is a woman's issue. Women are both the older persons for whom care is given and

the caregivers who provide the care. Although more male than female babies are born, women over the age of 75 outnumber men by a ratio of 100 women to 60 men. This disparity grows more marked in even older age groups. In addition, over 80% of all assistance provided to the elderly is provided by family, friends, neighbors, and church. Most of this care is provided by the wife, the daughter or the daughter-in-law. Traditionally, elderly persons lived with younger family members so that the women could provide the care. Now that women must work and are no longer in the home during the day, they are not available to provide the care as they did in the past. Many are trying to give assistance after work or on lunch hours; this is not sufficient. One of the many fields which have attracted women is health care - the professionals who care for the elderly as a job are also predominately female.

In addition, we must remember that families do not exist in vacuums - and families encompass all generations. Often the daughter who has the care of an elderly parent or grandparent also has the responsibility for teens who need care, time and attention to assist them to reach maturity in this far more complex and dangerous world.

Caregiving is often a 24 hour a day job - there is a famous book about the care of Alzheimer's patients which is entitled The 36-hour Day. That title accurately describes the demands and stress under which the caregiver exists. Often, when we are called to give assistance, the caregiver is in far more immediate danger of serious medical problems than is the patient whose every need is being immediately addressed. It is neither an exaggeration nor overly dramatic to say that we have seen caregivers die from the strain and labor of

24 hour a day care and the person for whom they were caring outlive them by five or more years.

For more than ten years, Aging Services has managed a program designed to assist persons over the age of eighteen years to remain in their own homes who otherwise would be in nursing homes because of chronic and acute medical problems. Called The Alternatives Program, its philosophy is that it is better and often less expensive for ill persons to be in their own homes, cared for by their families and loved ones, than it is for them to be in nursing homes or other institutions. It is far better to provide the caregiver with some, usually limited support and assistance, so that the situation remains intact, than it is for the family to become exhausted and decide that they can no longer continue with their caregiving responsibilities. Through The Alternatives Program, home health care, Meals on Wheels, transportation, Senior Companion Program, and other similar supportive services, our agency provides a wide range of services which constitute a system of community based long term care.

Our experience is that each element of the long term care system is badly needed. Nursing homes must be accessible when the medical or psychological situation has developed to the point that the caregivers can no longer cope or that 24 hour nursing care is required. More and more, nursing homes also serve as intermediate locations where persons go upon release from a hospital for a few days to recover from an illness or operation before returning home for more extended recuperation.

The availability of home health services provided by licensed or certified Home Health Agencies has grown dramatically in the past ten years. Services available from these organizations range from extremely sophisticated technologically oriented speciality services such as home dialysis or I V chemotherapy to nurses, home health aides and other medical professionals. These services often replicate those provided in institutions. But, because they are provided in the home of the patient or family members, the services can be limited to those which the family has neither the capability nor the energy to provide. Incredibly ill persons remain in their homes because of the love of their families and the expertise of home health agencies.

Supportive services, such as home delivered meals, respite care workers, transportation, and homemakers are also critical to the success of a community based long term care system. Often, the key factor in keeping someone at home is the provision of a meal, or assistance with bathing, dressing, money management and other simple daily tasks.

Case management is the glue which holds this system of services together. This is a system in which a professional evaluation is made of the condition and needs of the client - usually by a multi-disciplinary assessment team with both medical and social service expertise. An individualized case plan is then developed and services are ordered to meet the identified needs. Once the services are initiated, on-going monitoring of the service provision and the condition of the client is necessary. The intensity of the case manager's monitoring of the situation will vary greatly depending on the condition of the client and the level of support from family and friends which is available.

It is important that the case management agency be a disinterested third party to ensure that a minimum number of the most cost effective services are ordered and that the quality of the services provided is monitored sternly. In addition, the system of agencies, funding sources, rules and regulations governing these services is extraordinarily complex. They are often far too demanding for an older person or their caregiver to successfully work with. The case manager provides an on-going resource for the family or the patient to assist them through the bureaucratic maze. It also provides immediate assistance if the client's condition changes or an emergency occurs.

I have seen community based long term care and this combination of different services provided by different agencies perform miracles for very elderly, very fragile people and the families who love and want to protect them. One example: about a year ago I visited the tiny, shabby house of an elderly woman in South Salt Lake City, about one mile from here. She was in her early eighties, had gone blind with severe diabetes and had had several amputations on each leg because of gangrene. At that point, each leg was only about twelve inches long. Each stump was filled with gangrene and further operations were impossible. She was very simply dying of gangrene. Her two daughters were attempting to care for her but they had neither the technical skills not the stamina to provide all of the support she required. A nurse from a home health agency went each day to change her dressings - I cannot describe the odor nor her screams when I saw the dressing changed. A home health aide helped her to bathe and keep clean. A Senior Companion stayed with her while her daughters, who were providing round the clock care, got out of the home for a bit of respite. A case manager kept in touch with the situation and ordered changes in the services which she received as her

condition changed. Otherwise, the family provided her care. She died about a month after I saw her, still in her home and surrounded by her family. Her income was very small. Without the support to keep her at home, she would have been in a nursing home at far more expense to the federal and state governments.

As I've dealt with the issues related to support for persons in their late 70's and 80's, I have become increasingly convinced that it is the height of stupidity and bad public policy for us as a society to do anything which jeopardizes the health of older persons. The lack of necessary health care is not only immoral but it is also terribly expensive to the taxpayer. Older persons simply cannot bounce back from an illness or traumatic episode the way younger persons do. If they become ill, they are far more likely to need additional, more expensive care if their needs are not promptly met.

Therefore, it is imperative that public policy makers at all levels, Congressional, State, and local, recognize that there will be additional costs and additional expenditures to provide health care to elderly persons. There is startling evidence that the American public will support additional funding for services to meet this need. Rolling Stone Magazine published a poll of its readers in its edition of April 7, 1988. These readers are predominately baby boomers and their younger siblings - eighteen to forty-four years old. To "provide better/more affordable long-term care for the elderly" was the most often stated answer to the question, "Which one or two domestic goals would you say are the most important for the next president to address?" 32% of the respondents mentioned this. Obviously, Rolling Stone's readers are not the natural constituents of this system of care. This poll graphically

illustrates the pervasiveness of the concern and commitment of the American public to the needs of the elderly.

The correct challenge is not how to keep costs down regardless of the consequences, but how to provide needed assistance most cost effectively. As a society, we have decided that we can no longer afford to keep older persons who are ill in the hospital and we are deciding that we cannot afford to keep them in nursing homes. The only place left to us is in the home. We must provide effective, low cost care in the home - but it must be readily available to those who need it.

First, care for the vulnerable and fragile must be comprehensive and must recognize that policy which impacts hospitals and nursing home services and utilization has a direct and forceful impact on the need for services in the community. The development of payment by diagnostically related groups for hospital care by Medicare has meant that many people are being released from hospitals "sicker and quicker". This policy has increased the need for community based health and supportive care enormously. But, there has not been a corresponding increase in support to meet this need.

When services in the community are designed, they must also be comprehensive and address the full range of critical needs of the elderly. Home health care is a major component, but the system must also include a full range of social and supportive services such as transportation, nutrition, and volunteer services like the Senior Companion Program in addition to home health care. Case management must be available to provide close coordination to ensure that all the needs of the individual client are addressed.

Elderly persons and their families must remain involved and responsible for caring for themselves and their loved ones. It is healthy to struggle to perform daily tasks. Too much assistance is as damaging as too little for it builds dependence and it is critical that older persons remain as independent as possible.

Change in a person's condition or need is often dramatic and unexpected. If only a minimum level of care is provided by outside agencies, there must be an entity available to consult with and order additional or different assistance if the condition of the patient or the needs of the caregiver change. A good case management program provides this insurance.

The reimbursement mechanism, not the needs of the client or the family has driven the design of the system. And the system, particularly Medicare, has been designed for acute, short term care rather than the chronic care which is the reality of the needs of the elderly. Policies which artificially limit the number of visits which can be made, terminate care when a condition is stabalized or improves, or force other funding sources to subsidize government supported care inhibit the provision of badly needed care to very ill persons and often encourage institutionalization at a far greater cost to the federal government.

More thoughtful attention needs to be given to the problem of how to ensure a high quality of care in services provided in the home. As the Commission on Legal Problems of the Elderly of the American Bar Association pointed out in its paper entitled "The 'Black Box' of Home Care Quality", the reality is that we know very little other than anecdotal stories about the quality and

standards of care provided in the home. But the stories indicate that better quality control is badly needed.

The payment mechanism is massively complex - most professionals have only a minimal understanding of the entire system and all of its rules and regulations. It should be made more simple and more manageable by the lay person. Too often, people become discouraged trying to work their way through the system and, as a result, needed services are not obtained. There are many who believe that this complexity is intentional - a device to keep costs down by discouraging utilization. The problem with this a a management tool is that it is the frail, unsophisticated and low income who are discouraged. They are the ones who need it the most.

Expanded funding and additional financial resources need to be developed. There are simply not enough services to meet the needs of the older population. Government funding must increase at the federal, state and local levels. Charitable resources must be expanded. And private long term care insurance must include payment for both in home and supportive assistance as well as nursing home care.

The value of community based long term care is that it provides care that is needed in the location in which the patient has the best chance of thriving - in a home environment. It is where people want to be - it is where their families want them to be. Simple help can do so much. And thanks to the efforts and leadership of far-sighted policy leaders such as yourself, we are gradually building a system which does protect and serve those to whom we owe so much - our parents and grandparents. Thank you for your help through these

last years. Please continue to assist us. Your efforts have been significant and, as with the expansion of the Senior Companion Program and the passage of the Health Care in the Home Act, successes are beginning to be seen. But we have not yet arrived at the end of our journey.

Senator HATCH. Thank you so much. I appreciate your kind remarks. I became an advocate for home health care back there because I saw the suffering that occurred. We had a couple of doctors from New York that started what was known as the Chelsey Experiment. They got the community, charitable organizations, doctors, and a whole bunch of others, and they brought home health care right into the home. They saved thousands and thousands of dollars.

And, of course, I get back to that story of Jamie Delgado who lives in west Salt Lake City, the little girl with cerebral palsy, just a very, very difficult life. But with the help of home health care, two separate surgeries, and physical therapy, this little girl who never had a chance to walk has now learned to walk. You know, my attitude is we should never let people like this down. That's a little girl, but I can tell you stories about senior citizens that really feel so much happier, so much more responsible, so much more alert, so much more like living that quality life because they had health care brought to their homes where they feel good, where they have a better chance.

It's people like you that I really admire, because you're out there at the forefront pushing and trying to educate people like me, so we can do the things that really need to be done.

I'm really happy we passed that little home health care bill. It was a much bigger bill. I had $100,000,000 in that when it passed the Senate. The House cut it down to $5,000,000, and they weren't going to let it pass. But we beat them up, and they had to pass it. [Laughter.]

But with that $5,000,000 we're going to have three to five demonstration projects to show once and for all that home health care works. We think it will save money. We think in the long run it will be cost effective, and if we can show that, then I think we can justify it. That bill alone is an authorization bill that can take a lot more money. So we have it on the books for the first time, and I hope from there we may be able to do what needs to be done in home care.

So it's people like you who have taken time to sit with politicians like me, who want to serve, who really deserve the credit. I just want to tell you that, and I appreciate your testimony here today.

Let's turn to Mrs. Lewis. We've invited you, Mrs. Lewis, because of your particular experiences. We know that you're not only a wonderful person, but you've suffered yourself. You've been caring for your husband for many years, and now you've had some difficulties yourself. But I'd like you to just take some time and give us your testimony to help us to understand what you've been through and how home health care might benefit you and others like you.

Mrs. LEWIS. Senator Hatch, ladies and gentlemen, my name is Marian Lewis, and I have lived in Salt Lake all my life. My husband and I have eight children, and I worked most of my life taking on a disability retirement from Kirkhams Tent & Awning in 1979. I had always thought the problem of home health care was something the other people had to deal with. Never did I dream the problem would be mine, but it is.

My husband, Bert, was a mechanic with Firestone. He retired in 1974. We looked forward to a happy retirement. We had hoped our

small savings, retirement pensions and Social Security payments would provide us with money to do the things we wanted to do. We hoped to have been a happy retirement like you read about in all the magazines, the golden years.

My husband was diagnosed as having Alzheimer's Disease by a doctor in March of 1987, but his problems began before that. He had slowly been losing his sight for several years. Because of this he worked at Industries for the Blind where he operated one of their saws cutting rubber pieces to make doormats. Even though he could not see very well, he was quite good at his job.

I first began noticing a change in him about ten years ago. The differences were very subtle at first. Slowly he was becoming mean and abusive to me. It was so unlike him. Bert had always been a sweet person. He never was mean to me.

Finally a year ago last March the staff at the Industries for the Blind called and told me that he did not recognize any of the staff or the other people that worked with him. He did not recognize where he was, and he did not know why he was there. I picked him up and made an appointment with the local doctor.

After an extensive series of tests, the doctor diagnosed Bert as having Alzheimer's Disease. Bert had surgery to replace one hip in 1962, the other in 1984. Before all of this happened the doctor told me that traumatic events like that sometimes act to set off a mild case of Alzheimer's to suddenly accelerate the symptoms and problems.

I have continued to care for my husband in our home since all of this has happened. I would not wish this terrible burden on anyone. It is the hardest thing I've had to do in my life. It gets harder with each new day.

As you can see I have my own health problems. I have severe arthritis. It's in my hands, my shoulders, my knees and spine. Sometimes the pain is so excruciating. I also have problems—I have blood clot problems. I have to have—I had to have my one knee joint replaced a few years ago. Last January my doctor told me I was going to have to have the other one replaced too. He said I would need to spend four weeks in the hospital before I'd be able to return to my home. I was not able to find anyone else to help care for me and Bert full time, so I postponed my surgery. Last month I was unable to postpone it any longer and went to the hospital on May the 4th.

I don't know of any places that I can turn for help. I have contacted the local Area Agency on Aging, and they have provided me with help for some of our problems. But they don't have the resources to help with all our home care health problems.

Through all of this I have had one bright ray of hope. When we found out Bert had Alzheimer's Disease I was referred to the local chapter of Alzheimer's Disease and Related Disorders Association—ADRDA. Before I entered the hospital, I turned to them for help and fortunately they were able to assist us. The Chapter had a small reserve of emergency funds which they were able to use for Bert's stay at the same convalescence center I was while I recovered from my surgery. ADRDA has been a godsend. Had it not been for them, I simply don't know what I would have done.

I'm afraid my problems are just beginning though. Bert and I are going home later today. He can still do a few things for himself, but he needs lots of help from me. I have to cut his food because he cannot see. But he can feed himself. I have to help him dress and undress and give him a bath. He can get into bed on his own, but I cannot push him in his wheelchair. It is going to be a while before I'm able to drive our car again, and that's going to make it difficult to get him to the Blind Center.

If he stops working at the Center, we will lose the few benefits they provide for us now. His most important benefit is the health insurance which is provided through Health Wise. Fortunately, this insurance covers our prescriptions which we only have to pay $2.00 for each prescription and $5.00 co-payment for the doctor. Believe me there is a lot of them. I have a lot of prescriptions. If I was to pay it out of my own pocket without the help of Health Wise, it would cost me $300.00 a month which is my Social Security check. That's not including my husband's medication. We don't have that kind of money.

But Bert receives $126.00 a month pension payment from Firestone for the 30 years of work he put in for work for them. Between our two Social Security checks we get another $831.00. We both have Medicare, Parts A and B. What little savings we used to have is long gone. The taxes on our home keeps going up each year and so does our utilities.

Bert is a veteran. He spent 37 months in a Japanese prisoner of war camp during World War II, but he can't get any benefits from the Veteran's Administration. The bills from our medical problems keep coming in, and I don't know how to get them paid. I don't know what we are going to do when we get back home later today.

When I had my other knee operated on a few years ago, it took me most of the day to do a load of laundry. I had to throw the clothes downstairs into the basement and scoot down the stairs one step at a time to get to the washer. I had to pull myself up one step at a time when I was done with each load. I don't think I can do that anymore because of my arthritis. I hope some day to be able to do all the chores for Bert that I did before this surgery, but I can't do them right now.

I don't know where to get the help we need while I'm recovering. And if I can, I don't think I can afford it. I don't know what the future holds for Bert and me.

Senator, I hope you can do something to help us and other people like us. You need to do something to cut the high costs of the medical bills. I think it's a horrible expense to be sick today. I also hope you can do something to help people to continue living in their homes. I think the assistance we need are simple, but they are so expensive and so hard to find.

Bert's doctor told me he will probably need surgery again soon. He also told me that he didn't think Bert would survive another operation.

Senator HATCH. You just take your time, Mrs. Lewis. You're doing really fine. We're proud to have you here, and we're proud to have your testimony. It's wonderful. And I think it helps us to understand just some of the problems that some of our senior citizens have as well as others. So you're doing great. You just relax.

Mrs. LEWIS. Bert isn't the same man I married anymore. And I don't want to lose him, and I'm afraid I will. And there is nothing I can do about it. I feel really helpless. I just want him to be able to live out the remainder of his days with peace and dignity.

I plead with you to do something to expand the home health care services that are available to people like us, so we can just have this one simple wish. Thank you very much for your attention. We really appreciate you.

Senator HATCH. Well, thank you. We appreciate you, and want you to know that I want to grant you your one simple wish—to get you more home health care. It is also one of my greatest wishes, and I fought for that ever since I have been there. We are making headway. And I want you to know that I agree with you that we have to do something about these rising health care costs. They're rising at double the rate of inflation, and that has to stop. We have to find some solution to that.

But first off, Mrs. Lewis, I want to praise you for your courage in coming here and appearing here this morning.

[Applause.]

Senator HATCH. Ordinarily back there we don't allow displays like that, but I kind of enjoyed that. We'll have to let that happen more often, but sometimes they are not that kind. But we're grateful.

We can see the people today have been moved by your testimony, and many of us have seen similar suffering by some of our senior citizens. My own two parents right here in the front row today—my dad's 84 and my mom's 82, and thus far they've been able to do pretty well for themselves, but they have to worry about these things too. I'm worried about them, and I want to make sure their quality of life is good and that yours is good. So we're going to keep working on home health care. Thank you for providing us today with such informative testimony.

Let me ask you a few questions, okay, if I may. As I understand it your husband was first diagnosed as an Alzheimer's Disease victim only one year ago; is that correct?

Mrs. LEWIS. Yes.

Senator HATCH. Now, you've been providing him, yourself, with services in the home; is that right?

Mrs. LEWIS. Yes.

Senator HATCH. Yes, you have. Have you received other types of health care services in the home such as Senior Companion or Meals on Wheels?

Mrs. LEWIS. No.

Senator HATCH. You haven't received those?

Mrs. LEWIS. No.

Ms. O'NEIL. Senator, we have more than 250 people on a waiting list for these programs. We've not received—admitted a new person to the Alternatives Program for more than ten months. We just don't have the money.

Senator HATCH. I love the Senior Companion Program and the Meals on Wheels Program, and we'll see what we can do about those because they're low cost programs that do an awful lot of good. They help those who are able to go and help in the home, and those who need the help as well.

I understand that you were just discharged from a nursing home yourself.

Mrs. LEWIS. I will be today. My husband and I both will go home today.

Senator HATCH. So your husband goes with you today.

Mrs. LEWIS. I won't leave him there.

Senator HATCH. What was the cost of this to you? Did you have a supplemental insurance policy? Have you been able to purchase such a policy for you and your husband?

Mrs. LEWIS. No. The only thing that saved us was the Alzheimer's Association. They paid for my husband's time in the nursing home while I was in the hospital and since I've been in the nursing home. And the Medicare picked up the ten days that I was in the nursing home. And I was informed yesterday that my Medicare had run out, so I have to go home. I have no other way to stay there to pay for it.

And they also told me that I need further therapy, at least three days a week. And that is—it's $96.00 for each therapy session. And I can't afford that. Medicare will pay 80 percent, and that's it.

Senator HATCH. You can't afford the 20 percent even. All right. Do you have to go to the hospital to get that done?

Mrs. LEWIS. Well, Hillhaven has a therapy class there, and it's really super. They've really been wonderful.

Senator HATCH. You have to leave your home?

Mrs. LEWIS. I have to leave there and go there three days a week.

Senator HATCH. You can see why I like home health care because it can bring you those sevices at a lower cost.

Mrs. LEWIS. They said they could bring it to the home. But I've had a lot of sciatic nerve problem, and they have this shock treatment that they give me. I'm there also to help my knee so I can bend it more and to get the swelling down.

Senator HATCH. I see. Now, Mrs. Lewis, if you had your way and you could get your one wish, what would you have this committee do for you and people like you?

Mrs. LEWIS. Just to help out whenever we need it.

Senator HATCH. So you love the idea and concept of home health care, but also catastrophic illness care as well.

Mrs. LEWIS. That's right.

Senator HATCH. I want to thank you and commend you for joining us today and for sharing your story with us. It's touched me. I wish you the best in your continued struggles.

We'll see what we can do back there, and I do hope to have a catastrophic health bill before the end of this year. We're working hard to do it. It's hard to come up with exactly the right bill that we can get everybody—or at least the vast majority—to agree with. But we're working on it and trying to do the very best we can. I hope that this Home Health Care Bill with three to five demonstration projects that I passed last year will really establish the importance of home health care, the cost savings that can occur, and the benefits that result in that type of care for people—especially people like you, good, honest, law abiding, decent people who are up against it and are having a rough time.

Mrs. LEWIS. But what has bothered me so much is that some of these insurance companies—like when my husband worked for Firestone—when he retired from there, the health insurance was supposed to stay as it was when he retired. And they have changed that so much we couldn't collect hardly anything from them.

So when he went to work for Industries for the Blind and got on their health care, that was a godsend for us because we didn't have to pay the full price for our medicine. Now, I don't think he's going to be there much longer because his health has really gone down. And when he leaves there, we are without insurance other than our Medicare.

[The prepared statement of Mrs. Lewis follows:]

THE NEED FOR COMMUNITY BASED LONG TERM CARE
A PERSONAL EXPERIENCE

REMARKS BY
MARIAN LEWIS

BEFORE
SENATOR ORRIN G. HATCH
SENATE COMMITTEE ON LABOR AND HUMAN RESOURCES
JUNE 3, 1988
SALT LAKE CITY, UTAH

Senators, ladies and gentlemen. My name is Marian Lewis and I have lived in Salt Lake City all my life. My husband and I have raised eight children and I worked most of my life, finally retiring from the O.C. Tanner Company in 1979. I had always thought that the problem of home health care was something that other people had to deal with. Never did I dream that it would be my problem ... but it is.

My husband, Bert, was a mechanic with Firestone; he retired in 1974. We looked forward to a happy retirement. We had hoped our small savings, retirement pensions, and Social Security payments would provide us with money to do the things we wanted to do. We hoped to have a happy retirement like you read about in all the magazines. Fifteen months ago Bert was diagnosed as having Alzheimer's Disease. Even before that I watched the shadow of my husband slowly disappear as Alzheimer's eclipsed the light from his life. He is mostly blind now, too.

My husband was diagnosed as having Alzheimer's Disease by a doctor in March of 1987 but his problems began before that. He had slowly been losing his sight for several years. Because of this he worked at the Blind Center where he operated one of their saws cutting rubber pieces to make doormats. Even though he could not see very well he was quite good at his job. I first began noticing a change in him about ten years ago - the differences were very subtle at first. Slowly, he was becoming mean and abusive to me; it was so unlike him. Bert had always been a sweet person, he was never mean to me. Finally, last March the staff at the Blind Center called and told me that he did not recognize any of the staff or other people that worked with him

there. He did not recognize where he was and he did not know why he was there. I picked him up and made an appointment with a local doctor. After an extensive series of tests, the doctor diagnosed Bert's problem as Alzheimer's Disease. Bert had had surgery to replace both his hips about two years before all this happened. The doctor told me that traumatic events like that sometimes act to set off a mild case of Alzheimer's, to suddenly accelerate the symptoms and problems.

I have continued to care for my husband in our home since all of this happened. I would not wish this terrible burden on anyone. It is the hardest thing I have ever had to do in my life, and it gets harder with each new day. As you can see I have my own health problems. I have severe arthritis. It is in my hands, my shoulders, my knees, my spine. Sometimes the pain is excruciating. I also have problems with blood clots from time to time. I had to have one of my knee joints replaced a few years ago. Last January, my doctor told me I was going to have to have the other one replaced, too. He said I would need to spend about four weeks in the hospital before I would be able to return to my home. I was not able to find anyone else to help me care for Bert full-time so I postponed my surgery. Last month I was unable to postpone it any longer and I wen into the hospital on May 4. I don't know of many places that I can turn for help. I have contacted the local Area Agency on Aging and they have provided me with help for some of our problems, but they don't have the resources to help with our home care problems. Through all of this I have had one bright ray of hope. When we found out Bert had Alzheimer's Disease, I was referred to the local chapter of the Alzheimer's Disease and Related Disorders Association - ADRDA. Before I entered the

hospital, I turned to them for help, and fortunately they were able to assist us. The Chapter had a small reserve of emergency funds which they were able to use to pay for Bert's stay at the same convalescence center I was in while I recovered from my surgery. ADRDA has been a godsend. Had it not been for them I simply do not know what we would have done.

I'm afraid my problems are just beginning, though. Bert and I are going home later today. He can still do a few things for himself, but he needs a lot of help from me. I have to cut his food because he cannot see, but he can feed himself. I have to help him dress and undress. He can get into bed on his own but I cannot push him in his wheelchair. It is going to be awhile before I am able to drive our car again and that's going to make it difficult to get him to the Blind Center. If he stops working at the center we will loose the few benefits they are providing to him now. His most important benefit is his health insurance which is provided through Healthwise. Fortunately, this insurance covers our prescriptions and we only have to pay $2.00 each for them, and believe me there are a lot of them and they are not cheap. If I had to pay their full cost it would be almost $300 a month. We don't have that kind of money. Bert receives a $126 a month pension payment from Firestone for the 30 years he put in with them. Between our two Social Security checks we get another $831. We both have Medicare, Parts A and B. What little savings we used to have is long gone. The taxes on our home keep going up each year, and so do our utility bills. Bert is a veteran - he spent 37 months in a Japanese prisoner of war camp during World War II - but we can't get any benefits from the Veteran's Administration. The bills from our medical problems keep coming in and I don't know how I'm going to pay them.

I don't know what we are going to do when we get back home later today. When I had my other knee operated on a few years ago it took me most of the day to do a load of laundry. I had to throw the clothes downstairs into the basement and then sit down on the steps and scoot down them one at at time to get to the washing machine. I had to pull myself up one step at a time when I was done with each load. I don't think I can do that anymore because of my arthritis. I hope to someday be able to do all the chores for Bert that I did before this surgery, but I can't do them right now. I don't know where to get the help we need while I am recovering and if I can get it I don't think I can afford it. I don't know what the future holds for Bert and me.

Senator, I hope you can do something to help us and other people like us. You need to do something to cut the high cost of medical bills - I think it's horrible how expensive it is to be sick today. I also hope you can do something to help people continue living in their own homes. The kinds of assistance we need are simple but they are so expensive and so hard to find.

Bert's doctor told me he will probably need surgery again soon. He also told me that he didn't think Bert could survive another operation. Bert isn't the same man I married anymore but I don't want to loose him. I am afraid I will, though, and there is nothing that I can do about it. I feel so helpless. I just want him to be able to live out the remainder of his days on earth in peace and dignity. I plead with you to do something to expand the home health care services that are available for people like us so that we can have just this one simple wish.

Thank you so very much for your attention.

Senator HATCH. Thank you so much for your testimony.

I'd like to go to Shauna O'Neil. I'll pick this up because I think it's a little bit behind, so let me just kind of hold it up here and show you this chart with some statistics on home health care.

The purpose of this chart is to identify home health care savings. For example, it would cut approximately $8,425.00 for inpatient hospital care for treating a cerebral palsy seizure. Yet, if we provide them treatment in the home, it would cost only $4,867.00. You can see the difference between home health care and institutionalized care. That's why I'm talking so strongly for home health care.

Now, Ms. O'Neil, this demonstrates the financial savings that we can achieve from giving home health care services in the home for those of us who have to stay at home or choose to stay at home. Now, why do you think there's such a resistance to some of these programs?

Ms. O'NEIL. I think policy makers are afraid that essentially it's a bottomless pit. They start funding home health care, and the financial drain will go on forever.

Senator HATCH. I guess they're afraid that it's going to become an entitlement program and continue to escalate.

For instance, let me just show you the difference. Take a neurological disorder. If we treat it outside of the home in institutionalized care, the average cost is going be about $17,783, with most being paid by taxpayers, perhaps. If we treat it in the home, it comes down to $196. That's a real difference. Of course, these are instances that we want to show.

Take spinal cord injuries. Outside the home you're talking $23,862. In the home we think we can provide the same services for $13,931.

Look at this one—born with breathing and feeding problems. If you do institutionalized care in a hospital, it will cost about $60,970 for this type of care. Yet, if we do it in the home, it's going to be $20,000. It's still expensive, but it's only a third of the cost.

Now, if we can do this without making it an entitlement program, but make it so it really does work, we could have significant cost savings to our budget across the board. I think that's something this chart shows, as well as the advantage of home health care. That's why we're fighting so hard for that particular program.

I remember when I first came up with the ideas on some of the home health care programs. The Congressional Budget Office, which we rely upon to determine economics, came up and said it would cost $3,000,000,000 more if we went to home health care. They didn't take into consideration any of the savings and so forth. We're now trying to educate the Congressional Budget Office as well as the Office of Management of Budget which is the big budget office for the Federal Government.

Well, can you please tell us from your experience working with the aging population what some of the emotional benefits of home health services really are?

Ms. O'NEIL. I think Mrs. Lewis very graphically exemplifies the spirit of the wife or daughter who is determined to care for the loved one at home. But that is a 24 hour a day job, so the stress, the pressure of having to be in the home on call at every moment

is enormous. But at the same point that person feels that they have given up a truly religious obligation if they give in and allow institutionalization to take place.

I've had people almost in tears thank me for some assistance in the home, so they can go to the grocery store or go to the bank. Going to the grocery store is about the low point in my week. [Laughter.]

But just the ability to get away and take a deep breath is just so terribly critical. The ability to have help and know that kind of care the person you love so much needs is available. People aren't trained to change dressings. They're not trained to safely help a person who has real difficulty moving in and out of a bathtub. And there's a real fear they're going to injure or going to damage, and indeed they do do that because of lack of knowledge, or they're injured themselves. What it does is allow the person, the family member, to continue to do what they want to do which is provide the care in the home.

Senator HATCH. I appreciate that. There are currently proposals before Congress to provide long-term care benefits to senior citizens. I'm sure you're aware that the primary concern is the cost of such plans.

Do you have any suggestions as to how society should pay for these plans, or should we step back and look at the public and private sector efforts to develop a national long-term health care program?

Ms. O'NEIL. It has to be a partnership. We as a society are going to be paying more. Things such as the recommendation in the Pepper Bill that the cap be lifted off the Medicare payments on Social Security tax. I think that is an excellent idea.

But at the same point insurance has to be broadened, and we need to have more policies which provide coverage for home health as well as nursing home care. We need to get some of the limitations in terms of availability of that policy—of those policies off. But I think that's a period of time.

Senator HATCH. I have a bill presently pending in Congress to expand the supply of child care programs. Is there a need for these types of care programs?

Let me expand that. Is there a need for adult care programs? In other words, we talk about child care—and I'm having a real battle trying to get that done in an appropriate way that will be a concensus bill. It's meshed in politics and everything else—but is there maybe a need for adult care in addition to child care?

Ms. O'NEIL. There really is. We need both expanded day care, so that people that are not quite as ill but can't really stay at home alone can go to a place such as a child daycare program. And that place providing them with protection and care. Programs such as the Senior Companion Program, we provide individuals to go in and stay in the home of very ill people so that the family can get out and take a deep breath. That deep breath, that walk in the park, that trip to the grocery store often holds that situation together.

Senator HATCH. Let me just ask one final question. And that is what do you foresee as the major problem that the senior citizens are going to have coming into the year 2000?

Ms. O'NEIL. Paying for health care.

Senator HATCH. You think that's the major problem?

Ms. O'NEIL. Uh-huh.

Senator HATCH. Well, I just want to thank both of you for coming. And I want to come over and just thank you, Mrs. Lewis, and tell you how much I appreciate you. We've known each other for a long time. I love you too. I know this was very hard on you. You are a wonderful wife, I'll tell you.

[Recess.]

Senator HATCH. If we could get this started again. We have two final great witnesses. In fact, I'm very grateful for the witnesses who have appeared so far and for those of you who are here.

By the way, I have some T-shirts that have been given to me by the American Cancer Society, "Smoking is for the birds. Cough, cough." [Laughter.]

Some of you may want to come up afterwards. I'll give them out to the extent that I can. I'm going to keep one for myself, however. I'll wear that in the Senate gym when I work out. [Laughter.]

Our final panel will provide us with insights on the health problems of depression and substance abuse. Approximately 10 million Americans suffer from depressive disorder over the course of a lifetime. One-fourth of all women and one-eighth of all men will suffer from some depressive disorder.

Depression can be as severe and disabling as heart disease, and like heart disease, depression can be successfully treated. Our primary goal then is early detection and treatment.

I'm pleased to welcome back to Utah our own Dr. Lewis Judd, the new Director of the National Institute of Mental Health. He's going to discuss the problems women face as a result of the disease of depression.

Finally, we will discuss legislation to continue the Alcohol, Drug Abuse and Mental Health Block Grant set-aside of 5 percent. This funds state programs which provide services to women who abuse alcohol and drugs. I look forward to the testimony by Nikki Lovell representing the Ogden Junior League, who will discuss federal, state and private sector efforts to expand treatment and prevention programs for women.

At this point I'd like to begin with Dr. Judd. I want to personally thank him for coming back to our home state of Utah, and I want to show special recognition to you in this very important position you hold—the leading position in health in this area in our country.

As you can see, we have two of the top leaders in America in health here today. Both of them have served here in Utah, and both of them are serving well in Washington. They are highly respected all over the world. So, we Utahans provide some very good people back in Washington.

I just have to say one other thing. Our new Deputy Attorney General is now completely in charge of the Justice Department as Mr. Meese travels, speaks, and does all that is expected of the Attorney General. He—a Utahan—runs the day-to-day operations of the Justice Department.

As you can see, we can go on and on about Utahans who are leading back there in Washington. We feel this state has really had

a dramatic impact on our country, not the least of which has been the impact that Dr. Lewis Judd has brought to Washington and the National Institutes of Health. So, Doctor, I'll turn to your actual testimony and listen to you at this time.

STATEMENTS OF DR. LEWIS JUDD, NATIONAL INSTITUTE OF MENTAL HEALTH, DIRECTOR, U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES, ROCKVILLE, MD, AND NIKKI LOVELL, OGDEN JUNIOR LEAGUE, CHAIRPERSON, WOMAN TO WOMAN PROJECT, OGDEN, UT

Dr. JUDD. Thank you very much, Senator Hatch. I'm very, very pleased to be here today and honored to be able to testify at this hearing. I'd like to commend you and the committee for the focus of the hearing, for it's timeliness, and it's importance, and really for what I have felt has been a very informative and very moving hearing.

We at the Institute have been involved in and have had a high priority with regard to women's health issues which is the focus of this hearing. And we feel we have rather good news to report to the committee in this regard.

Over the last 25 years we've made some major inroads in understanding depression through basic and clinical research which has been conducted by the NIMH, which as you noted, is the lead scientific institute in the federal spectrum focusing on mental disorders and mental illness. We've discovered over time that depression is a very specific, discrete, clinical entity. We're shown that it is the result of a combination of interaction between genetic and environmental factors which are mediated by the brain. And we have discovered with our epidemiologic surveys that depression and depressive illness, as we're calling it at this point, is a very, very common disease.

As you noted, it affects 6 percent of the population, the adult population at any one time—that is, approximately 9 to 10 million Americans with depressive illness. We've learned, as well, that even though depressive illness is not exclusively a disease that strikes women, women are afflicted twice as often as men. And in virtually every mental health epidemiology survey that has been conducted in countries across the Western world, this 2 to 1 ratio has held up. So it is very clear that, for a variety of reasons, depressive illness does afflict women in much, much higher proportions than it does in men. So it is a major issue for women.

Senator HATCH. Why is that, Doctor?

Dr. JUDD. Well, at this point there have been several different hypotheses. It appears to us that it may be basically a biological issue. That's because the various psychosocial hypotheses that have been proposed and studied have not been upheld consistently through empirical research. These include, for example, the lower status of women in Western societies, both socially and economically; the concept that some women possibly may have been conditioned in a "learned helplessness" model which might promote a proclivity to depression; or what is called the "role overload" hypotheses, in reference to women who are responsible for managing

families and who are responsible also for careers at the same time, which may subject them to enormous stresses.

Senator HATCH. That comes down to many women are working in our society today. And they work all day and then come home and have to work the rest of the day. And men seem to—we do our eight hours, or whatever it is, and——

Dr. JUDD. And come home scott free.

Senator HATCH. Come home and watch TV.

Dr. JUDD. Yes. We've found though, that these explanations do not apparently contribute to the increased prevalence of depression among women. The disease does appear to be a biological phenomenon. At least we're leaning in that direction.

Senator HATCH. You lean towards most depression as being a derivative of some biological problem?

Dr. JUDD. It is basically a combination, as I indicated, of a genetic vulnerability that people inherit to one degree or another and the interaction of that with the environment which then elaborates over time.

Senator HATCH. I think that's a healthy approach, between you and me. And I think that's going to lead to more help in this area than ever before. I'm glad to hear you saying that.

Dr. JUDD. One thing we would like to tell the committee and you personally because of your leadership role in the authorization of funds that have come to the Institute for the study of depression, that we do have here a major scientific success story. I noticed you asked Dr. Smart what the payoff has been in the war on cancer, and there have been enormous payoffs. Certainly in the war we're mounting against mental illness major successes now are occurring, one of which is in the area of depressive illness.

For example, at this point we now can very reliably diagnose depression. We know the pathophysiology of depressive illness and some of the underlying brain mechanisms that subserve and create depressive phenomena.

We have been able to develop rational and very effective methods of treating depression. One well-researched and effective method of treatment involves the use of antidepressant medications. Thirty years ago there were only a handful of them. Now almost 40 of them are available, all extremely effective. They are used as our primary method of treating severe depression.

The Institute also has developed pyschosocial treatments that are extremely effective in more mild to moderate kinds of depressive illness.

We're at a point now in our history where we can manage effectively 80- to 90-percent of the depressive illness that presents to us. This has enabled us to mount a major prevention and education campaign that I want to tell you about. The Depression/Awareness Recognition, and Treatment Campaign, or D/ART, was launched by the NIMH on May 3 of this year at a national press conference at the National Press Club in Washington.

Senator HATCH. Are you going to leave that with me?

Dr. JUDD. I would be delighted to. The focus of the D/ART campaign is obviously depression. We see three action steps as necessary. One is awareness, increasing public awareness of the disorder, and also health providers' awareness of its frequency. Two, is

increasing recognition of the specific signs and symptoms of depression. Third, is making available appropriate treatment.

We're reaching out with this campaign now across the Nation to those 10 million individuals, who are seriously depressed at this point. Six million of these individuals are women, and two-thirds of them are untreated. They're living in misery, despair and dysphoria.

The impact of depression on their lives exposes them to much higher rates of job loss, much higher rates of marital discord and divorce, and to death by suicide—we know that 1 in 7 individuals with serious depression will commit suicide. So we're reaching out to them with this campaign. The message is very simple, but we feel a very profound one.

Depression is not merely experiencing the blues, it's not just the vicissitudes we all experience in the human condition, the ups and downs. It is a serious illness. It is common illness. It is often unrecognized. It's often undiagnosed and untreated. But there is hope, because very effective treatments exist in the form of antidepressant medications and psychosocial treatments. These often are used together to great effect. Thus, finally we can help most people with depression, the vast, vast majority of them. Mounting this campaign was not only possible and timely, but was a public heath inperative.

This is a first in our field, Senator Hatch. In the hundred year history of modern psychiatry this is the first research-based prevention and education campaign that has gone out to the public. And we're modeling it after the National Heart, Lung and Blood Institute's Campaign on Hypertension that was so successful in the early 1970's and continues to be very successful. We feel convinced that with the partnerships we've created across the country, and with the emergence of the science in the field that is delivering very effective diagnostic and treatment techniques for depression, we will do as much good with this campaign as virtually any other.

We also are confident, given the emergence of strong science in our field, that we are at the point that there will be a number of other prevention campaigns very much like this down the road.

I would like to acknowledge the role that the state of Utah has played in this. One of the five training centers in the D/ART Campaign which is focused on training mental health and health providers in the state-of-the-art diagnosis and treatment of depression is here at the University of Utah. One of our fifteen national Community Partners is the Mental Health Association here in the state of Utah. Both of those entities are doing a superb job at this time.

I would like to close my testimony, Senator, with the comment that we are proud at the Institute of what we've achieved. We're very grateful and would like to acknowledge the role of this committee and your own leadership in providing strong and farsighted support of the Institute research programs. These have made it possible for us to initiate the D/ART Program. I'll be pleased to answer any questions you might have.

[The prepared statement of Dr. Judd follows:]

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DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service

Alcohol, Drug Abuse, and
Mental Health Administration
Rockville MD 20857

TESTIMONY OF

LEWIS L. JUDD, M.D.

DIRECTOR

NATIONAL INSTITUTE OF MENTAL HEALTH

ALCOHOL, DRUG ABUSE, AND MENTAL HEALTH ADMINISTRATION

PUBLIC HEALTH SERVICE

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

before the

COMMITTEE ON LABOR AND HUMAN RESOURCES

June 3, 1988

Mr. Chairman:

I am Dr. Lewis L. Judd, Director of the National Institute of Mental Health (NIMH), which is a component of the Alcohol, Drug Abuse, and Mental Health Administration, Department of Health and Human Services.

I appreciate having this opportunity to appear before the Committee to comment on one of the premier accomplishments of this Nation's biomedical research enterprise: The development of knowledge which enables us to diagnose accurately, treat effectively, and, in many instances, prevent the recurrence of clinical depression, a severe disorder which affects some 9.6 million Americans in any six-month period.

The topic of depression is particularly germane to the focus of this hearing on women's health concerns. We know that depression, both major depression and dysthymic disorder, occurs at significantly higher rates in females than in males; the female to male ratio, as determined by rigorous diagnostic criteria, is approximately 2 to 1. In bipolar, or manic depressive disorder, a third subtype of mood or affective disorders, we know that rates experienced by males and females are more nearly equal.

Applying the 2:1 ratio to the 9.6 million figure which I cited suggests that, right now, some 6 million women are experiencing a clinical depressive disorder which requires treatment. Effective treatments exist for the vast majority of these patients. We know, however, that about two-thirds of all persons who experience a depressive disorder receive no treatment from any source. The disease goes unrecognized and untreated

until it runs its course--often at great cost to patients' families, their general health, their marriages and jobs, and, even their lives. One in seven persons with a diagnosed depression eventually will die by suicide, a waste that is all the more tragic because it is preventable. Let me note, parenthetically, that males are at higher risk for completed suicide.

Among the hypotheses for the gender difference are numerous psychosocial and/or biological etiologies. Psychosocial hypotheses, by and large, have not been supported by empirical research. These include, for example, learned social helplessness in women, the impact of the housewife role, failure to maintain self-esteem when a marriage fails without an alternative career, and the difficulties of managing both family and career while working.

Given our increasingly precise characterization of depression, and the evidence that gender differences are real, the role of biological variables seems a more promising path of investigation. Of particular interest are genetic studies which support X-linkage for affective disorders in some families, and I will comment in a moment on our scientific progress and plans in genetic studies, both epidemiologic and molecular.

We also are seeing research advances in precise documentation of the association between Late Luteal Phase Dysphoric Disorder (LLPDD), a diagnostic entity which represents a refinement of what previously had

been referred to as "premenstrual syndrome," or PMS, and depression. In research reported last month at the American Psychiatric Association meeting, NIMH-funded investigators from the University of Pittsburgh presented data showing that 55 percent of women with LLPDD had histories of major depression, and this was increased to 75 percent in women with history of both major depression or dysthymic disorder. They also found that one-third of women with LLPDD had a history of post-partum depression, a rate which is double the reported life-time prevalence of 10- to 15 percent.

With respect to post-partum depression, it is known that transient depressed feelings are common immediately following childbirth and that the six-month period after birth carries a heightened risk for emotional disturbance. While it is important that we recognize that in addition to biological changes, other stresses such as adjusting to a new infant, sleep disruption, and related marital problems may contribute to mood disorders, the fact remains that the most common point at which major depression occurs in women is following childbirth.

I want to emphasize that we have much yet to learn. On the other hand, scientific evidence we now possess suggests strongly that the sex differences observed in depression are not artifact; that it is improbable that psychosocial events alone are the cause of these differences; and that biologic variables will be shown empirically to be significant factors in the special vulnerability of women to depression.

Now, in these introductory comments, I have drawn on a vast accumulation of research on the affective disorders. I wish to highlight information of interest to this forum, but I also believe that it is important to view and understand these issues in the context of the larger body of research on depression.

What we know today of depression reflects a scientific success story, one that is the outgrowth of many years of basic and clinical research. As is true of the vast preponderance of research on mental disorders which is conducted in this country, our studies of the depressive disorders have been supported primarily by the federal government, through the National Institute of Mental Health, with funds authorized and appropriated by the Congress.

As a result of this investment, we are able to inform the American people that help for those suffering depression is available. We do so with the same degree of scientific certainty that the National Heart Lung and Blood Institute possessed when in 1972 it mounted its highly successful National High Blood Pressure Education Program

In the remainder of my statement, I first will review, in some detail, what we mean by "clinical depression." I then will offer an overview of the array of scientific disciplines and areas of inquiry which have contributed to our current knowledge base regarding depression. Against this backdrop, I would like to describe a new and exciting undertaking--the Depression Awareness, Recognition, and Treatment (D/ART) program--

which is designed to put the information we have obtained into the hands of the American public and our Nation's health care providers.

Depression Defined

Although most persons are familiar with and frequently use the term "depression," many would find it difficult to differentiate the normal mood of depression that all of us experience from the syndrome of clinical depression, a serious, incapacitating disorder.

All of us have ups and downs, good days and bad days, and experience disappointments and losses. We react to these vicissitudes of life with many emotions, among them sadness and depression. Sadness is normal. We are biologically programmed to interact with and to become attached to specific other people. These "attachment bonds" are at the heart of family and society. It is adaptive, not abnormal, to feel sadness at separation and to be bereft in the face of interpersonal loss.

In attempting to define where normal sadness ends and clinical depression begins, it is useful to think of a spectrum along which boundaries from point to point are blurred, but opposite ends are strikingly different. Clinical depression is a syndrome that is distinguished from depressed mood in several ways. For one, rather than being "transient," the syndrome is persistent: diagnostic criteria require that major depression be recognized for at least two weeks, but, untreated, it can persist for months and even years, and interfere significantly with one's ability to perform the normal tasks of living.

Clinical depression also is differentiated from depressive mood by the presence of features that one might not associate with a "psychological" condition. These may include appetite or sleep disturbances, lack of energy, loss of interest and ability to engage in sex, physical aches and pains, and difficulty concentrating. These somatic features are accompanied by feelings of low self-esteem and worthlessness, suicidal thoughts and behavior, and, all too frequently, by suicide. Our studies have shown that one in seven persons with a depressive disorder eventually will commit suicide.

The concise list of the symptoms of clinical depression that I have suggested should not be permitted to obscure the extraordinary amount of human misery that depression creates for the patient and for those who are close to one who suffers the illness. The toll of depression impacts on the very ability of an individual to function as a spouse and as a parent and as a friend. Not infrequently, it leads to academic difficulties, higher rates of loss of jobs, and increased marital difficulties and divorce.

Until very recently, these latter types of signs and difficulties were essentially all that was understood of mental disorders. Lacking a scientific data base, we were reduced to explaining and even diagnosing mental illnesses in terms of reactions to life's adversities. Such explanations fostered a perception that illnesses such as depression signified weakness of character.

The ongoing scientific revolution in the study of the brain and of the fundamental biological processes which underlie cognition, affect, and behavior has had a dramatic impact on our concepts of the nature of mental illness and our capabilities and responsibilities in responding to people who experience mental illnesses.

Let me take a moment and review the many areas of research which have contributed to our current ability to recognize and treat clinical depression appropriately and effectively.

Scientific Advances in the Study of Depression

Relevant research advances can be described in several broad categories: diagnosis, epidemiology, treatment, health services and service systems, and mental health economics. Underpinning much of our progress has been a sustained investment in scientific studies designed to elucidate the pathophysiology of depressive disorders.

Psychopathology, Classification, and Diagnosis

A fundamental requirement in researching a disorder is an ability to characterize that disorder precisely so that investigators can be certain that phenomena they are studying are indeed relevant to the disorder in questions. In recent decades, psychopathology research has led to new diagnostic criteria which, in turn, have facilitated refinements in diagnostic instruments.

In the 1960s, for example, the United States/United Kingdom (U.S./U.K.) project demonstrated the wide discrepancy in diagnostic practices for affective disorders and schizophrenia that had developed in the two countries. This information prompted the development of the St. Louis Research Criteria and the Research Diagnostic Criteria (RDC), which eventually evolved into the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders, Third Edition. I should note that this manual recently has been revised, signalling further refinement of our diagnostic precision in the field of mental disorders.

The development of specific criteria for all mental disorders, including major depression and other forms of affective illness such as bipolar disorder and dysthymia made possible the design of the NIMH Diagnostic Interview Schedule (DIS). This instrument, which enables increased precision in communication between clinicians and research investigators, was used earlier in this decade in the NIMH Epidemiologic Catchment Area, or ECA, survey.

Epidemiology

The ECA project to which I just referred is the most sophisticated survey ever conducted of the nature and extent of mental disorders in this country. Over 20,000 adults, age 18 and over, who resided both in the community and in institutional settings, were interviewed in five demographically diverse U.S. communities.

By combining the number of persons with at least one of the three disorders which I mentioned, six-month prevalence rates for any affective disorder were found to be 5.8 percent and life-time rates were 8.3 percent of the population. When these rates are applied to the estimated population of 165 million non-institutionalized adults in the U.S., the total number of people affected is seen to be between 9.6 million with recent (six-month) prevalence and 13.7 million with a life-time history of a depressive disorder.

In the continuation phases of this study, investigators are following persons identified as having disorders, both those who do and do not enter into the treatment system. The data which are collected will afford us an improved understanding of the consequences of treatment and an appreciation of how individuals not receiving professional care cope with their conditions. This type of epidemiologic data will be used in helping to define research needs and priorities, in allocating mental health care resources, and in improving the quality of mental health care overall.

Already, our epidemiological research has identified sociodemographically defined groups at high risk for clinically significant depressive disorders these disorders.

Sociodemographic correlates and risk factors: A summary of ECA findings reveals, as I noted earlier, that the rate of affective disorders in women is approximately twice that seen in men; that persons aged 25 to 44 are at highest risk for depression; that the 65-and-over age group have the

lowest risk; and that individuals who are separated or divorced are two and one-half times more likely to suffer a depressive disorder than are individuals who are married. Recent research has suggested, however, that discord between currently married couples increases risk. When all other variables are controlled, no significant differences are seen on the basis of race-ethnicity or high or low socioeconomic status.

Increasing prevalence among younger cohorts: Analyses of several recent epidemiological and clinical studies of depression have found both higher overall rates of depression and an earlier age of onset of depression among younger cohorts, suggesting that the rate of depressive disorder may be rising in successively younger age groups. Although a definitive prospective longitudinal study has not been undertaken to confirm these retrospective analyses of cross-sectional studies, the conclusions are a cause of concern, particularly in light of the burden of illness these disorders currently represent.

At the other end of the life span, depressive illness is recognized as a major cause of morbidity and mortality in old age. One measure of the extent of depression among the elderly is that people over 65, who comprise less than 12-percent of the population, account for nearly 19-percent of suicides. Although rates of depression are significantly lower for both sexes in the 65-and-older age group, the possibility exists that the cognitive symptoms of a depressive disorder--for example, the slowed thinking and difficulty concentrating--may be misinterpreted, resulting in a misdiagnosis of dementia. Given the existence of effective treatments,

it is particularly important that we devise methods of analyzing depressive symptoms in the elderly.

Genetics: The recently reported findings of genetic transmission of bipolar disorder among an Amish family has confirmed the strong probability of a genetic predisposition in some people for developing a depressive disorder. How the genetic and other biological factors of age and sex interact with environmental exposures, such as the stress of marital divorce or separation, has yet to be explicated in a manner that would permit us to intervene directly and prevent the first occurrence of a depressive disorder.

Let me go into a bit of detail, and mention in this context that an exciting and promising new study on the genetics of depression and schizophrenia at the molecular level is being conducted here in Salt Lake City with support from the NIMH. I am referring to a project, begun in April, that is directed by Dr. William Byerley, at the University of Utah, in collaboration with scientists at the Howard Hughes Medical Institute.

Although we know that heredity plays a role in the major mental disorders, we do not know what precisely are the genetic factors involved or the mode of inheritance of these factors. On the other hand, recent advances in molecular biology, such as those used in the study of the Amish family to which I referred, make it possible to identify the approximate chromosomal location of the gene or genes that play a role in these illnesses.

In order for us to exploit the technologies, it is necessary that families in which the illnesses in question have occurred in multiple generations participate in research. Through the participation of these families, scientists are able to establish permanent cell lines and then use the marvelous new methodologies we possess to identify genetic abnormalities that may shed light on the etiology, or cause, of a disorder and on ways of intervening at the molecular level.

Treatment Efficacy Research

A primary objective of being able to diagnose disorders with great accuracy, of course, is to be able to treat those disorders with comparable precision. To that point, within the past few years, our scientific programs have made possible an extraordinary expansion and refinement of an array of treatment modalities for the depressive disorders.

Psychopharmacology: The solid base of research evidence documenting the effectiveness of psychopharmacological treatments for the depressive disorders--bipolar illness and major depression--constitutes one of the most important chapters in the history of psychiatric research.

Tricyclic antidepressants (TCA's) and related drugs currently are the pharmacologic treatments of choice for major depressive episodes, with recovery rates with these medications in the range of 70 to 80 percent. For those 20 to 30 percent of patients who fail to respond to these medications, a substantial range of alternative treatments, including

lithium and thyroid supplements, have been evaluated to potentiate the effectiveness of the tricyclics.

Lithium carbonate has been studied extensively in multi-center clinical trials sponsored by the Veterans Administration and the NIMH. These and other studies have established the value of lithium in treating acute manic episodes and in preventing recurrence of bipolar and unipolar depressive episodes.

While monoamine oxidase inhibitors represent another "first generation" antidepressant medication of proven efficacy, I should note that much of our research in the area of psychopharmacology for depression now is focused on the refinement of "second generation" agents which will offer increased efficacy while reducing side effects.

Psychological Treatments: Research on psychotherapeutic approaches also has been productive, yielding a number of new, short-term therapies which are focused on symptom reduction and are highly interactive between therapist and patient. The course of treatment with such therapies as cognitive/behavior therapy and interpersonal therapy usually is in the range of 16 to 20 sessions. These and other psychological approaches complement and, increasingly, supplant reliance on the long-term, predominantly psychodynamic approaches of the past. Many of the new approaches have been standardized by treatment manuals and explicit training procedures for therapists, thus making them amenable to rigorous evaluations.

Other Approaches: Somatic treatments including electroconvulsive therapy (ECT) and pharmacological treatments for the prevention of recurrent mood disorders recently have been the subject of NIH/NIMH Consensus Conferences which summarized the current state-of-the-art in use of these therapeutic modalities. Other additions to the array of somatic treatment options include light therapy, used in managing depressive disorders with marked seasonal variation, and clinical manipulation of sleep patterns, a form of intervention which has been shown to induce temporary remissions in depressed unipolar and bipolar patients.

I view as particularly promising, Mr. Chairman, the fact that our emerging comprehension of the basic biological processes which underlie depression now are contributing directly to further innovations in treatment. Clinical investigations which recently provided evidence of the value of anticonvulsant medications such as carbamazepine and valproic acid in the treatment of bipolar disorder were inspired by an understanding of basic processes in this disorder.

Elucidating the Pathophysiology of Depressive Disorders

Indeed, the study of fundamental brain processes perhaps has been the most critical source of new information regarding depression and related disorders. It has made it possible for us to delineate with increasing precision the neurobiological links between symptoms of depressive disorders and factors that ultimately cause the illness.

With respect to the role of neurotransmitters in depression, for example, monoamine hypotheses of depression formulated in the 1960s led to a broadened understanding of the modulatory and integrative functions of the amine system as well as other neurotransmitters such as gamma aminobutyric acid (GABA) and acetylcholine and, in turn, to progressively more refined hypotheses of specific neurotransmitter abnormalities in the various subtypes of depression.

In the 1970s, the discovery and characterization of neurotransmitter and drug receptors and the finding that receptor function can be studied in readily available peripheral tissues such as blood elements or skin fibroblasts made possible research on the intracellular effects of drugs in the brain. This information today is facilitating the design of new antidepressant agents with high potency and specificity.

Use of neuroendocrine strategies in the exploration of pathophysiology accelerated rapidly following the isolation of specific peptides responsible for the brain's control of pituitary hormone release. This work has pointed to the usefulness of "challenge" tests in which use of a biological measure as an independent variable permits examination of its clinical, pharmacological, genetic, and other biological correlates.

And, as I suggested earlier, recent years have been marked by a resurgent interest in the dysregulation of sleep and other biological rhythms in depressive disorders, with this research prompting innovative new types of clinical intervention in the short-term while encouraging intensive

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examination of a range of aberrant biological cycles and their role in affective disorders. The implications of cyclicity are further heightened by work with animal models that has suggested mechanisms which may help explain patterns of recurrence of depressive disorders as well as possible links between biological and psychosocial precipitants of illness.

Although research on biochemical abnormalities in depressive disorders have been predominant in recent decades, the advent of diverse functional brain imaging techniques has spurred interest in identifying and assessing neuropathological correlates of the disorders. Evidence remains sparse, but reports of secondary mania associated with physical illness and/or trauma assures continued use of these new technologies in contributing to a delineation of the pathophysiological chain and, ultimately, to defining the etiology of the depressive disorders.

Clinical Services and Health Systems Research

In anticipation of the concluding section of this statement, let me acknowledge that advances in the diagnosis and treatment of depression such as those highlighted above have not revolutionized treatment practice to the extent that one might expect. In 1982, the NIMH Collaborative Program on the Psychobiology of Depression, a large, multi-site study, provided sobering evidence that despite availability of effective treatments, these may not be applied appropriately, even in the hands of psychiatrists and other mental health specialists.

In this particular project, more than half of the depressed patients who were encountered during the study were found to have been treated with anti-anxiety agents rather than antidepressants prior to presenting for treatment at tertiary care centers participating in the study. Patients included those with severe, protracted depression. Only one-third had received any antidepressants, and only about one in ten had received adequate doses. Even after entering the tertiary care centers only three-quarters received any antidepressants.

Research conducted over the past decade also has documented patterns of mental health service delivery and has yielded a clear picture of the responsiveness of our service system to depressed patients. Here, the news has not always been encouraging.

Location of Treatment: The ECA data demonstrated where individuals with specific mental disorders were actually seen and whether or not they went for mental health services. The majority of individuals diagnosed with a depressive disorder--that is, the 5.8 percent of the population in any six-month period, to whom I referred earlier--are seen in multiple professional settings during an episode of illness. Some 19 percent of patients with depression are seen in the specialty mental health sector and 10 percent are seen in the human services sector; the vast majority, however, 74 percent, are seen in the general medical sector. We also know that approximately 21 percent of those with depressive disorders are not seen in any service setting.

Treated Prevalence: In addition to identifying the types of settings in which individuals with depressive disorders were seen for some type of service, we also have been able to determine whether they sought and obtained mental health treatment specifically. What we have learned in this regard is that although patients with more severe disability have higher treatment rates, the potential for early intervention in the majority of cases clearly is not being realized. Whereas three out of four persons with a diagnosed depressive disorder are seen in the general medical sector during the course of an episode of illness, only one in four of those individuals receives a mental health service from their physician.

Treatment Intensity: One additional finding which I would mention points to the primary care sector's potential value as a site for recognizing and treating depressive disorders. Our studies show that people with depressive disorders make outpatient visits to health and mental health care facilities at approximately three times the average rate of all persons who use those facilities.

If I were asked to summarize what we have learned from these various pieces of the health service delivery puzzle, my response would be that we have defined where individuals with depression are being seen, identified the nature--including the shortcomings--of the treatment they receive, and thus we have a new awareness of the need to tailor special and continuing medical education programs in ways that will be most useful for mental health and general medical personnel.

The Economic Cost of Depression

A final area of research I would mention involves studies on the economics of mental illnesses which have underscored the urgency--and the potential benefits--of undertaking an aggressive effort to ensure the availability of appropriate, high quality care for depressive disorders.

In a recent analysis of the direct and indirect cost of major depression, it was estimated that the total direct in-patient and out-patient treatment costs for this single affective disorder was $2.1 billion. The indirect costs incurred from lost productivity, because of morbidity and mortality, as well as additional expenses for family care, were estimated at $14.2 billion, raising the total social cost estimate for major depression to $16.3 billion per year.

The shift of even a small proportion of the $14 billion in indirect costs into direct treatment costs could produce a profound improvement in the lives of those individuals with clinical depression who currently are untreated or undertreated.

The D/ART Program: Depression Awareness, Recognition, and Treatment

Mr. Chairman, I have described depression and reviewed the extraordinary yield--in information, in new and refined treatment techniques, and in strategies for reducing and eliminating the clinical and societal sequelae of major depression--of our national investment in scientific research into mental disorders.

We have accomplished a great deal. Yet the most critical marker of our progress will be the extent to which we are able to convey the information to those who will use and benefit from it. It is to meet this challenge that we have launched the Depression Awareness, Recognition, and Treatment (D/ART) campaign.

The D/ART campaign is the first major U.S. public health prevention program targeted on a specific group of mental disorders. The action steps--Awareness, Recognition, and Treatment--signify that the goal of the program is to address the morbidity and duration of depression and related disorders through early identification and treatment. Early clinical intervention, to induce rapid remissions, and adequate maintenance treatment, to prevent relapse, have great potential for decreasing the prevalence of depression.

The message of the D/ART campaign is straightforward:

- Clinical depression is a common disorder that usually is unrecognized. When identified, it can be treated.
- There are effective pharmacological and psychological treatments which often are used in combination.
- The large majority of clinical depressions, including the most serious, improve with treatment, usually in a matter of weeks.

The campaign consists of two major components, focused respectively on professional education and public education. The professional education

phase was initiated in 1987 when the D/ART program staff at NIMH initiated continuing education training programs for providers well in advance of the launch of the public education campaign. A grant program was developed to assist universities and medical schools to provide short-term training in the diagnosis and treatment of depressive disorders to primary care physicians, nurses, and occupational therapists as well as to psychiatrists, psychologists and social workers.

I would point out that one such training program is being conducted under a three-year grant awarded to Naomi Silverstone, M.S.W., at the University of Utah. The purpose of this particular grant is to provide state-of-the-art training to 300 health and mental health professionals in Utah, Wyoming, Idaho, and Montana. Approximately one-half of the trainees will be physicians, in primary care and psychiatry, and the other half will be psychologists and social workers.

Clearly, in the inter-mountain west, vast geographic distances constitute a formidable challenge in allocating resources and delivering services. A core feature of this particular training project is the emphasis placed on the development of a team approach to the treatment of depression.

At six sites, the training team will provide instruction in biological and psychotherapeutic theory and interventions to all 300 participants. The complete array of psychopharmacologic interventions and two models of psychotherapy--interpersonal therapy and cognitive-behavior therapy--will be reviewed, and then physician and non-physician providers will be

provided supervised opportunities to work as a multidisciplinary team in staffing clinical cases.

This is one of five training grants the Institute awarded nationwide, yet through these programs, a course on the diagnosis and treatment of depression has been offered somewhere in the United States every week over the past year. The courses are intended to serve as models and to stimulate more extensive programs under private auspices.

In preparation for the public education phase of the D/ART campaign, NIMH staff reviewed the literature and obtained survey information on public attitudes and knowledge about depression. We found that while most people are reasonably knowledgeable about the mood symptoms of depression, they are less likely to know about the changes in psychomotor state, energy, sleep, and the range of physical symptoms.

Virtually everyone who responded to our surveys believed that treatment would help, most also believed that a depressed person could get better through their own efforts. This belief was echoed in a recent Roper poll in which only 12 percent of respondents indicated they would take medication for depression; 78 percent said they would live with it until it passed. Many persons said they would not seek treatment because they feared a negative impact on their employment situation; even more cited the perceived cost of treatment as a deterrent to seeking care. This last issue is a crucial one requiring research and policy guidance and the

informed participation of many sectors, both public and private, to assess its impact.

We recognize the need for broad support of and participation in the D/ART campaign. Toward meeting this need, we have enlisted a group of campaign consultants and a community partnership program to carry out the program.

Our consultants include representatives from all the major mental health professional associations; health and mental health organizations; businesses, including pharmaceutical companies; labor, religious and educational groups; and mental health advocacy groups.

The community partners have been developed in collaboration with the Mental Health Association and the Alliance for the Mentally Ill and have been organized to implement the D/ART program in 10 regions of the country. Individuals within both of these groups are working to identify sources of private support to distribute print and electronic materials and are arranging to host talk shows, to encourage the development of professional seminars on depression, and to make referrals to treatment facilities.

Again, I am pleased to be able to note that one of our active partners at the State level is the Mental Health Association of Utah. Tia Davis, of Salt Lake City, is the D/ART chairperson.

The public education component of the task, and the role of our Community Partners, is all the more challenging and essential because we live in an era when individuals have assumed increasing responsibility for their own health. The ability to recognize the symptoms of illness, the confidence to query one's physician or other health care provider, and the persistence to seek and obtain appropriate care all require information.

Conclusion

Mr. Chairman, I offer this account of our progress in the understanding of depression with considerable pride, and I describe our program of education and prevention with considerable confidence. Yet I recognize that clinical depression is a heterogenous disease that reflect multiple, extraordinarily complex, interacting systems. Even today, we must exercise restraint in stating our accomplishments. At the same time, we must and will persevere in the task of education, to encourage persons who are depressed to seek help, and to better enable clinicians to respond to patients appropriately with the tools and knowledge that are presently available.

I thank you for the opportunity to testify at this hearing. I am pleased to answer any questions that you and the members of the Committee might have.

Senator HATCH. I'm just delighted to have you here.

We have Tia Davis in the audience here today that manages the D/ART Program. We're very happy to welcome you here.

We're proud of your program, Dr. Judd. Too many years have gone by where people have not looked at depression through the eyes that you have just described to us. I am glad to see an outreached type of approach like you're making because I think that it's time for people to realize these matters can be helped in the vast majority of cases. It's just a matter of working to do so. You've brought a lot of hope here to this hearing today, to both women and men, but especially to women because of the higher incident of depression relating to the greater pressures and maybe different genetic inheritances that exist between women and men.

I happen to have some questions for you, but I'd now like to turn to Ms. Lovell before we ask any questions.

Nikki Lovell is from the Ogden Junior League, and she's going to discuss the Junior League's efforts to reduce substance abuse among women in Northern Utah and throughout the country. We're happy to have you here and look forward to your testimony.

Ms. LOVELL. The Junior League of Ogden would like to acknowledge all of the work you have done that's made the work we've down even easier. The 5 percent set-aside has encouraged not only Ogden, but many leagues throughout the nation to do this project in their communities.

In January of 1986 the Association of Junior Leagues with Allstate Insurance Company put together the Woman to Woman Program which is basically an alcohol education program. Our initial task was to survey communities, especially to survey the gatekeepers (those people women go to for help) to understand what their perception was, what services were available, and what was needed. We in Ogden put together our survey and have completed it along with the other original 30 sites in the nation.

When we first attended the conference in Atlanta to begin this project, people were shocked to see Utah, particularly in a women and alcoholic project. It's interesting to note that out of the statistics Utah's findings matched the national findings.

Senator HATCH. We have serious problems with alcoholism and drug abuse in this state. It's one of the reasons that I've become so interested in it. I was before I went to the Congress though because I had worked with people in my legal career who had these difficulties. I really appreciate people like the two of you. Continue. I'm sorry to interrupt you.

Ms. LOVELL. After we did our original survey, we needed to make the community aware of our findings. We launched a prevention campaign on women and alcohol nationally with some TV spots and some information going out through magazines.

After that, each of the communities, 30—and there are now 80 leagues throughout the nation and Mexico that are participating in this program and have set up model programs. But our findings are what we base this effort on.

Our No. 1 finding was that the need for child care for women in treatment was paramount. Many studies reported that a substantial number of women entering treatment were responsible for the caretaking as well as the financial responsibility of their children,

more so than men were. We also found that often women enter treatment because they were inadequate as parents due to alcohol's effects and they were seeking help.

A question that we have wondered about in Ogden and throughout the nation is when women enter treatment, they jeopardize the family life. If they put their children into foster care, they oftentimes lose the option to have them returned upon completion of treatment; whereas, if they had entered a treatment center for cancer and were in remission, they would come out there would be no question their children would be returned. But upon returning home with the remission with alcoholism, oftentimes what took place before, the neglect, maybe sometimes abuse, has an influence. And this sometimes jeopardizes their ability to regain the rights to care for their children.

Senator HATCH. That may be a reason why some women don't get treatment.

Ms. LOVELL. Oftentimes.

Senator HATCH. Well, that's wrong. We ought to change that.

Ms. LOVELL. Definitely.

Senator HATCH. I'm very glad you brought that to our attention. You say child care would be very helpful for women seeking alcoholism treatment.

Ms. LOVELL. Through our study the number one need throughout the nation for women to seek treatment is child care.

Senator HATCH. Boy, am I going to use that testimony. I hadn't even thought about that. We're thinking so much about the huge general child care problems. I've been saying conservatives have got to get their heads out of the sand; and they've got to realize that if we love families and children, we ought to be doing the very best we can to recognize that some women have to work. Now, you're saying some women, who have this dependence on alcohol, could lose their children. They need to be able to go for alcoholism treatment without the fear of losing their children. That may be an incentive to go if they knew they weren't going to lose their children.

Ms. LOVELL. Definitely.

Senator HATCH. I have to admit these hearings are wonderful because that brings it to our attention like never before. Go ahead.

Ms. LOVELL. We also feel that the children of these chemically dependent people need to be treated themselves. They are oftentimes biologically or genetically predisposed to addiction themselves, so they need some of the prevention information and education that should take place while their parents are in treatment. We felt like this could possibly be one of the truest forms of prevention to work with these children.

Senator HATCH. That's good.

Let me ask Dr. Judd just for a minute on that point. That would be the same with regard to depressive illness or psychiatric illness. Some women and men may refuse to go get treatment for fear they'll lose their children.

Dr. JUDD. That's correct.

Senator HATCH. So child care would be important there as well.

Dr. JUDD. Absolutely.

Senator HATCH. Keep going, Ms. Lovell. I'm sorry to interrupt you.

Ms. LOVELL. That's all right.

Senator HATCH. We wanted to get some substantiation as well from Dr. Judd.

Ms. LOVELL. Our second finding was the need for education for women about alcohol use. We found there was a real void in the information on women and alcohol. New findings over the last ten years have told us that alcohol reacts differently in a woman's body than in a man's; therefore, we need to address those issues and make sure that the women are aware of them.

In Ogden our league chose to sponser a conference. And with your help we were able to put on a very successful conference. One of the national speakers that spoke to us told us that there have been three day conferences on alcohol in the past, and that maybe one session has been dedicated to talking about women. Our conference was all day, and we had 24 speakers on women and substance abuse.

Senator HATCH. That's great.

Ms. LOVELL. So we felt like that conference was the beginning. And we really do want to thank you for the help you gave us in making that happen.

Senator HATCH. Thank you.

Ms. LOVELL. We also are the pilot project for the workplace. The Junior League of Ogden took on this project, and our focus has been the federal workplace. We designed an Improvisational Theater Troupe that will visit work sites and not only entertain, but provide information on alcohol to women. It's been very successful for us. We also verified the fact that many of the audiences that we talked to had no knowledge of the effects of alcohol. We also verified the fact that they also did not know about resources, how to talk to women, what to do about the problem if they did uncover it.

We had one of the professionals in our audience who had invited us, told us that even when they do know when and where to go, that oftentimes you'll find the women sitting outside the door crying, still afraid and reluctant to enter for help. This is why we feel the Woman to Woman Project is a tremendous success, because it is going out and talking to women and getting women to talk.

Our third finding was the need for information and referral services for women. As I said, we originally started with 30 leagues. There are now over 80 leagues throughout the nation doing a prevention and education program on alcohol. What will happen is eventually it will uncover many women needing help, many women who need services. And although our prevention will be good, if those services are not available for those women when they come forward, we will not have done them a service by bringing that to their attention.

We do for this reason support some advocacy in three areas. We would like the continuation of the ADAMAHA block grant set-aside 5 percent for women who need alcohol services. We are very much in favor of that.

We also favor Women's Health Legislation that includes information about the gender-specific impact of alcohol on female health

and includes provisions for gender-specific alcohol and drug abuse prevention and education, as well as treatment that meets women's needs. We hope that women are not just put into treatment programs that are originally designed for men, but that they are put into treatment programs that are specifically for women.

We also support the drug-free communities money, and that some of that money be used to educate women. Because we speak here from Utah, it's important to make note of the fact that Utah has a significant problem with prescription abuse. So we recognize here in Utah that we need to make not just an alcohol awareness program, but we need to look at the issues that surround prescription misuse, and that there needs to be an ongoing program to educate physicians throughout the country on that problem. As we find drugs to be of benefit to us, we also recognize that they can be a tremendous danger to us.

We also look now at a population of teenagers that is drinking more, accepting the drug as commonplace more. It is not something that is a taboo anymore for teenagers. And with that comes the existence of girls drinking equally with boys. And now we can recognize the consequences of that through teenage pregnancy, fetal alcohol syndrome, fetal alcohol effects, suicides and accidental deaths.

Because of these problems Woman to Woman is something that we have started at junior leagues throughout the country, but we will need a lot of support through legislation and through programs throughout the communities.

We thank you for the work you have done and hope that much more can be done in the future.

Senator HATCH. We appreciate the testimony you've given. I'm going to ask Ms. Lovell some questions first, and then I'm going to end with Dr. Judd.

I just want to say I'm proud of all the work that you and the Junior League up there in northern Utah have done. You've really done a very good job. And just please accept my appreciation for what you've done for our state.

Can I ask one question. What benefits have you seen as a result of the 5 percent set-aside in the Alcohol, Drug Abuse and Mental Health Services Block Grant which I wrote into the grant?

Ms. LOVELL. Throughout the nation junior leagues have been involved in looking at what the 5 percent has done. Some of them have benefited directly with the program we've started in communities. We have seen education prevention programs started in communities that were not there for women. We have seen some special emphasis on the effects of fetal alcohol syndrome these last months. We're seeing programs start for children of alcoholics and for mothers who have children. We're also seeing residential treatment for women that allows for child care as well as gender-specific approaches. These are all new programs, things that were not there before set-aside monies.

Senator HATCH. That's great. Do you have any suggestions for changes in that particular part of the legislation?

Ms. LOVELL. More money. [Laughter.]

Senator HATCH. You know I hear that all the time. [Laughter.]

Ms. LOVELL. I was afraid of that.

Senator HATCH. I just wish we could solve that problem. You stated that one of the primary problems that women face in seeking treatment for alcoholism and drug abuse is child care. How have the junior league programs throughout the country addressed this problem, and do you have any suggestions as to what we might be able to further do?

Ms. LOVELL. We have some junior leagues that have started child care for women who are in treatment. The child care they have sponsored has included a Children of Alcoholics Awareness Program as well as caring for the children while their parents are in treatment.

We have some junior leagues that opened up residential treatment throughout the nation that are providing for child care while the women are in treatment as well as providing child care while women are in the outpatient treatment.

So the junior leagues, because that is our number one goal, have done a lot in the child care area.

Senator HATCH. That's great. I want to commend you and just tell you how much we appreciate your testimony today. You've been very articulate and very all embracive as far as I can see in the short time you've taken.

Let me go to Dr. Judd finally. I can't begin to tell you how important it is for us here in Utah to have someone of your stature come back to the state as the leading authority in the National Institute of Mental Health, the person that runs that big division. I just want to publicly congratulate you on this new position as the Director of the National Institute of Mental Health.

Dr. JUDD. Thank you.

Senator HATCH. It is indeed my pleasure when Utahans who are as gifted as you are selected for great leadership roles in our country. It's an honor to this state and an honor to all of us.

Dr. Judd, you highlighted the fact that research has helped us identify that help is available to those suffering from depression. Can you elaborate just a little bit more on the D/ART Program here in Utah, and how the D/ART Program is making this information available, and how a person suffering from depression can get help here in Utah.

Dr. JUDD. The D/ART Program is all encompassing. It started several years ago on the basis of the scientific advances. At that time, we began to prepare a network of Community Partners throughout the United States that would help take on the dissemination of the information. In parallel, the Institute staff began to develop press packages like this with pamphlets, suggested stories for newspapers, and developed public service spot announcements for both television and radio. It is my understanding that the local Community Partner will probably kick off the D/ART Campaign with a press conference alerting the media to this, urging exposure through the media of what depression is and that help is available. The Community Partner program will encourage people to get treatment, in part by supplying lists of symptoms and signs of depression, and also lists of suggested places where individuals can get help. These settings will range from standard mental health clinics to one's primary care physician.

The D/ART Campaign has recognized, as we at the Institute recognize, that not everybody is aware that we are at a point where we can treat effectively 80 to 90 percent of depressive illness if the disorder is diagnosed accurately. We're finding through our surveys that only 25 percent of individuals with depressive illness are actually being treated in the mental health system, that 75 percent of them are being seen in other systems—mainly in the medical system at this time—but only a fraction of the individuals are receiving appropriate treatment.

Thus, we have developed a specific campaign of education to upgrade the knowledge of primary care and general physicians as to what depression is in the modern concept and how to approach it in a rational way to treat it effectively. We've tried to work at all levels to insure that this would happen.

There was recently coverage of the D/ART Campaign in Parade Magazine that went out nationally. It was an interview with me, alerting people to the campaign. And I can report to you that the mail was delivered to my office in boxes and is still coming in at this point. So the need is out there, and we're urging our Community Partners, including the Mental Health Association of Utah, to begin the campaign now.

Senator HATCH. That's great. Well, I as an employer operate a set of offices. I had the D/ART Organization come into the office for an awareness and information seminar for employees on depression. You've done the same thing as an employer.

Dr. JUDD. Yes, we have.

Senator HATCH. It seems to me we want to urge other employers to do the same thing. It might be very helpful to them.

Dr. JUDD. That is a very important point because we figure that over $14 billion a year is lost from depressive illness indirectly through time away from the job and the various sequelae from depressive illness. We will be contacting soon, as was done with the National High Blood Pressure Education Campaign, the chief executive officers of all the major corporations across the United States to bring this to their attention, to indicate we have a full campaign available for them, and urging them to take this on in a major way throughout the United States.

Senator HATCH. Dr. Judd, you listed various groups of people that are at high risk for clinical depression. Can you explain the reasons for the increased rate of depressive disorder among younger Americans.

Dr. JUDD. This has been a very recent phenomenon that we still have under study at this point. But our most recent scientific studies have indicated that, first of all, there seems to be evidence of an increase in the incidence of depression as contrasted with survey results ten years ago. So that is a trend that we don't fully understand, but we're attempting to elucidate why this might be.

Secondly, we are detecting depressive illness earlier and earlier. At one point it was felt that this was a disease that affected people primarily between ages 25 and 35. We're now finding as we get better and better at diagnosis, we're picking up the disorder earlier. We're not sure whether or not there is an absolute increase in numbers among young people who are depressed, or whether our capacity to identify this with a high degree of precision means that

we are beginning to recognize and diagnose it where previously we did not.

We have this under study. If it indeed is true, then we'll have to look at the antecedents of it. But all we have right now is that the phenomenon exists.

Senator HATCH. Let me just ask one further question. What further research emphasis should we turn to in the fight against depression, and what suggestions do you have to me as to what we might do better on Capitol Hill to help in this great fight?

Dr. JUDD. Well, there are several suggestions I would have in this regard. First of all, continue the support and the leadership that you have given to the research efforts of the National Institute of Mental Health. Your vision helps make campaigns like this possible.

But in terms of specifics, it's very clear we've entered a new era with our knowledge and understanding of the brain. In some ways it's one of our great biomedical frontiers, and we feel that research in this area has had enormous payoff. And in many ways it's restructured and changed the mental health field. We are urging strong support of basic and clinical neurosciences and study of brain functions and brain mechanisms.

In addition, we feel there will be very high payoffs on the genetic studies we've conducted. Already, molecular genetics has had a major impact in the study of mental disorders. Rather recently, NIMH scientists identified gene linkages on the human chromosome that code for depressive illness. We feel that molecular genetics is a major area that needs to be pushed—it's also an area that the University of Utah has a major grant in. Investigators at the University are studying all mental disorders, but with specific emphasis on depressive illness. Those are the areas we feel must be pushed at this point because we feel we can unlock the secrets. Even though we know a great deal about this, we need to know more.

Senator HATCH. I'm glad to have your testimony. I just want to tell you that I think that the people of this State ought to be proud of the University of Utah Medical School and the quality of people we have there. I can't remember the total of medical experts they have up there, but it was 300, as I recall.

Dr. JUDD. Oh, yes, indeed. A very fine resource available to this State and this region.

Senator HATCH. Well, some people are worried that because of the important political issues this year, the tax limitations and so forth, we're going to lose this tremendous advantage we have in having one of the truly great medical schools in the world. I'm concerned about that having worked closely with the medical school, having worked a lot on bringing a lot of funds into the University of Utah School.

Dr. JUDD. That's correct.

Senator HATCH. Utah State, B.Y.U., Weber State and others are providing some very excellent scientific work in some of these areas.

Dr. JUDD. That's indeed true. These are marvelous facilities that take many years and decades to build. And once lost, it's almost impossible to rebuild them.

Senator HATCH. Like you say, it's a resource that we are known throughout the world for. I don't think the general public here in Utah really fully understands that as what it is. I was talking to Chase Peterson, President of the University. He's worried to death if we don't handle these tax programs right, we could lose the tremendous advantage we have. I'm concerned about it too.

I would like you to wait. I want to chat with you just a little bit after we're through if you could. I know you are busy.

Dr. JUDD. I'd be delighted.

Senator HATCH. If you can, I'd appreciate it.

At this time I'd like to submit for the record "Women's Health Styles" and also a statement on the "Health Care for an Aging Population and the Future Role of the Obstetrician-Gynecologist" submitted by Jan Schneider, Medical College of Pennsylvania; Sarina J. Grosswald, with The American College of Obstetricians and Gynecologists; Howard G. McQuarrie, our own obstetrician, gynecologist here in Salt Lake City, Utah; Mary Jo O'Sullivan, and M.D. for the University of Miami; Daniel M. Strickland, with the United States Air Force; and Harrison C. Visscher, The American College of Obstetricians and Gynecologists.

All of these are doctors except for Sarina Grosswald who has a Masters of Education. This record has been submitted by Dr. Howard G. McQuarrie. I just want to thank him for bringing that to us to put in the record at this particular time.

[Due to printing limitations, the pamphlet "Women's Health Styles" was retained in the files of the committee.]

[The report "Health Care for an Aging Population . . ." follows:]

HEALTH CARE FOR AN AGING POPULATION AND THE FUTURE ROLE OF THE OBSTETRICIAN-GYNECOLOGIST

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Medical College of Pennsylvania
Sarina J. Grosswald, M.Ed.
The American College of Obstetricians and Gynecologists
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Salt Lake City, Utah
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Abstract

As life expectancy has increased, the rising number of older people has converted the traditional population pyramid into a rectangle. The health care needs of an older population will demand new directions of the medical profession. The American College of Obstetricians and Gynecologists (ACOG), the specialty organization for approximately 25,000 obstetrician-gynecologists in the U.S., assigned a committee to explore the future role of the specialty in adapting to an aging population. The following is a summary of a report that studies means of synchronizing health care needs with health care resources and recommends approaches for preparing for the future.

Key words: American College of Obstetricians and Gynecologists
Aging
Continuing Education
Educational Strategies

Introduction

Aging of the U.S. population, frequently referred to as the greying of America, is having a profound impact on our society.[1,2] More people are living longer, fuller, and active lives. At the same time medicine is being influenced by a move away from hospitals, by decreased funding and increasing competition, by new technology, and by the physicians' search for professional satisfaction.[3,4,5,6] As a means of prospective planning, The American College of Obstetricians and Gynecologists (ACOG), the specialty organization for 25,000 obstetrician-gynecologists in the U.S., assigned a committee to assess the future role of the specialty in adapting to the aging population, and to make recommendations for future ACOG continuing medical education. In exploring the issue, it became clear that aging would affect not only the general population but also the physicians rendering care; and the aging of both will affect professional practice. It is for this reason that the question is aproached from the perspective of change rather than solely as a consequence of aging.

Though the focus of this article is the specialty of obstetrics and gynecology, the dynamics of demand and changes in practice that are explored will certainly have an impact on other facets of health care, and will have broader implications on areas of industry and commerce as the country adjusts to being an older society.

Changing Health Care Needs

In considering obstetrics and gynecology, the major focus of the committee was on women beyond reproductive age, i.e. in the *post-menachmeal* phase of life (see diagram). Increasingly, women in this group are healthy, have expectations of continuing health, challenge the concept that physical disability is inevitably associated with growing older, and have a larger base of knowledge about health.(7,8,9)

The health care of the post-menachmeal population can be considered in four categories: health, health maintenance, disease prevention, and disease management. The obstetrician-gynecologist plays a significant role in all four. The recognition of better health to an older age should influence physicians' attitudes about caring for this population. Women of even advanced years may anticipate physical, psychological, and sexual lives that are full and rewarding. The physician has a critical role in helping women maintain their health and remain active and vital through their older years. This includes educating and advising the patient about hormones and nutritional factors affecting health. Promotion of exercise programs to encourage mobility and physical activity further benefits health and improves bone strength. Psychological counseling renders new areas of concern for the physician, including sexual awareness, psychosexual dysfunction and its prevention, and emotional difficulties associated with physical change.

Probably the most critical role of the physician caring for an older population is to prevent disease that could erode a healthy and vigorous life. Disease management will involve recognition of disease, and treatment or referral as appropriate. As new information emerges about the physiology of an aging person, new horizons will open to the physician providing care.

Changing Health Care Resources

Health care resources, including the physicians themselves, are undergoing changes parallel to those of the population at large. These changes will dramatically affect practice patterns and the delivery of health care. The number and age distribution of practicing obstetrician-gynecologists in the future has been predicted with presumed accuracy. The number of older physicians is growing, more physicians are joining the specialty, and an ever increasing percent of obstetrician-gynecologists are women.(10) More difficult to forecast are the changes in the practice profile and day-to-day professional activities of obstetrician-gynecologists. Some changes have already started a pattern that is almost certain to continue.

1) Location of Professional Activity - An increasing component of gynecological health care delivery is in a non-hospital setting.(11) This centrifugal effect of health care delivery systems removes physicians from the traditional professional interaction that the hospital provides. Hospital specialty departments and the medical staff organizations in

the past have been sources of professional socialization and educational interaction. The shift away from the hospital must be considered when planning future educational activities.

2) Market Competition - The marketplace and the environment of health care are changing. As the number of physicians increases, new areas of competition and marketing will develop in a free enterprise system. The obstetrician-gynecologist will need to participate in this search for a market share. It would be unrealistic to deny that turf and territorial problems will arise as practice patterns change.

3) Cost Containment - Activity to reduce health care costs will continue to grow. With diminished fiscal resources a major challenge will be to ensure the delivery of adequate health care through efficiency. However, diminished fiscal reward and reduced economic expectations will alter both attitudes and practices.

4) Contractual Practice - More contractual agreements such as HMO participation may be anticipated as a norm, especially for younger practitioners seeking to reduce an educational debt. In addition, the increasing popularity of HMO insurance, especially among employers, forms a major factor in the expansion of this practice pattern.

5) External and Regulatory Factors - Increasing numbers of external forces will have an impact upon practice patterns. These include regulatory activities such as accreditation, licensure, and professional

certification. Some will be manifest through fiscal reimbursement and limitation of the range of professional activities and privileges and others by redistribution of patient flow. Medico-legal insurance costs, the fear of litigation, and the dramatic disruption of a lawsuit itself affect all facets of practice.

6) Technology - The impact of development of new technologies, both diagnostic and therapeutic, on management of health care needs is profound. Accompanying the growth of technology is an equally rapidly broadening knowledge base which makes it ever more challenging for the physician to maintain the information required to give optimal health care.

New technology is also bringing new approaches to locating and using medical information. The ability to immediately access available information at the time of patient care can significantly influence practice patterns.

7) Professional Satisfaction - All changes in practice patterns must be considered in light of physicians' professional satisfaction. Too little challenge carries the risk of boredom, while too much has the opposite risk of extreme fatigue and "burnout". The need for careers commensurate with patient needs and professional satisfaction must be recognized as essential components in preparing physicians for a changing role.

Synchronizing Health Care Needs
With Health Care Resources Through Education

The educational activities of The American College of Obstetricians and Gynecologists must respond to the changing health needs of society. To facilitate the synchronization of resources to needs, The College requires an understanding of current practice patterns, attitudes, and aspirations of its Fellows and an enlightened approach to influencing change through education.

Baseline data should be obtained to assess the sensitivity of physicians to changes in health care needs and their motivation to change practice activities. An effort should be made to determine what obstetrician-gynecologists know about managing the post-menachmeal population, areas of information physicians themselves perceive as requiring updating to keep abreast, and practitioners' perceptions of patient needs in the changing environment. This information can be used later to evaluate the effectiveness of educational strategies and to determine changes in practice patterns over time.

In devising mechanisms by which change can be achieved, education should be directed at both providers of health care and recipients of health care, i.e. the population at large. The recommendations of the committee focused only on the educational needs of the physician.

2) Educational Environment

To enhance the potential for change, the educational environment should correspond to physicians' needs. Therefore information should be provided in a variety of educational settings.

a) Group interaction - As previously noted, the dynamics of the health care system is moving physicians away from the hospital which has served a vital role in maintaining ongoing professional interaction. This shift must be recognized and efforts should be made to preserve the social and educational interaction of colleagues. One method may be encouragement of professional guilds by specialty, subspecialty, and interspecialty. Another might be to foster a network system of communication. Such a network would provide a mechanism for the exchange of information among physicians concerned with the health care of an aging population.

b) Individual instruction - New interactive resource systems including telephone and computer databases would bring immediate access to information for the individual practitioner. Other means of individual instruction might include television, cable, satellite, networks, and videotapes.

c) Practice based - To ensure that new knowledge is applied, it must be related to actual clinical practice. Physicians working together in groups could benefit from onsite education and consultation. Consultation teams might be used to visit practices and give assistance, direction, and redirection.

Efforts can be made to assist physicians in assessing their practice situation. A practice analysis kit might be developed, either computer based or paper based. Such a kit could provide a means for individual physicians to identify their current activities, future roles in the marketplace, and potential changes of practice style or health personnel that could meet these needs.

3) Physician Attitudes and Lifestyle

Meeting the challenges of the changing population should offer the obstetrician-gynecologist personal and professional satisfaction, as well as intellectual and environmental rewards. A shift in practice pattern can have a significant effect on the lifestyle of the obstetrician-gynecologist. In the changed practice pattern, diminished stress, decreased nightcalls, less litigation, and more predictability of work hours can be anticipated. The physician "burnout" problem in current practice is due to the harsh physical and emotional challenges of the specialty. Long working hours and the mental, physical, and emotional stress of obstetric practice are a reality. As physicians age, a shift from obstetrics to gynecology has been widely associated with a lifelong career in the specialty. Shifting the emphasis of a practice to meet the health care needs of older women can bring about a more graceful evolution of such altered practice patterns and thus meets the needs of the physician. Providers of education should adopt a role in encouraging change and in preparing physicians for new practice patterns and patient populations.

Conclusion

The future practice of obstetrics and gynecology will be influenced by the changing demography; and similar changes will be reflected in the microcosm of the specialty. There will be more women over the age of 45 living full and active lives. At the same time medicine will be influenced by a move away from hospitals, decreased funding and increased competition, new advances in technology, and the physicians' search for professional satisfaction.

The recommendations offered here can form the nucleus of an educational model which could not only be effective in responding to the changing demography, but can be modified and applied to other health issues lending themselves to educational solutions. Health care needs are changing in many areas and the task of synchronizing educational resources to these needs is formidable. It is to this challenge that these recommendations are directed.

Nine specific recommendations for action are offered. The American College of Obstetricians and Gynecologists should:

1. Take a leading role in preparing its Fellows for changing responsibilities and an expanded role in health care as demographic changes result in an aging population.

2. Coordinate educational activities directed at both the providers and the recipients of health care.

3. Establish a database of current practice patterns, attitudes, and aspirations of its Fellows.

4. Monitor changes in practice patterns, attitudes, and aspirations of its Fellows as demographic changes evolve, to assess whether educational strategies achieve their stated purposes.

5. Devise educational systems that not only disseminate new information but also include teaching the skills of managing new information.

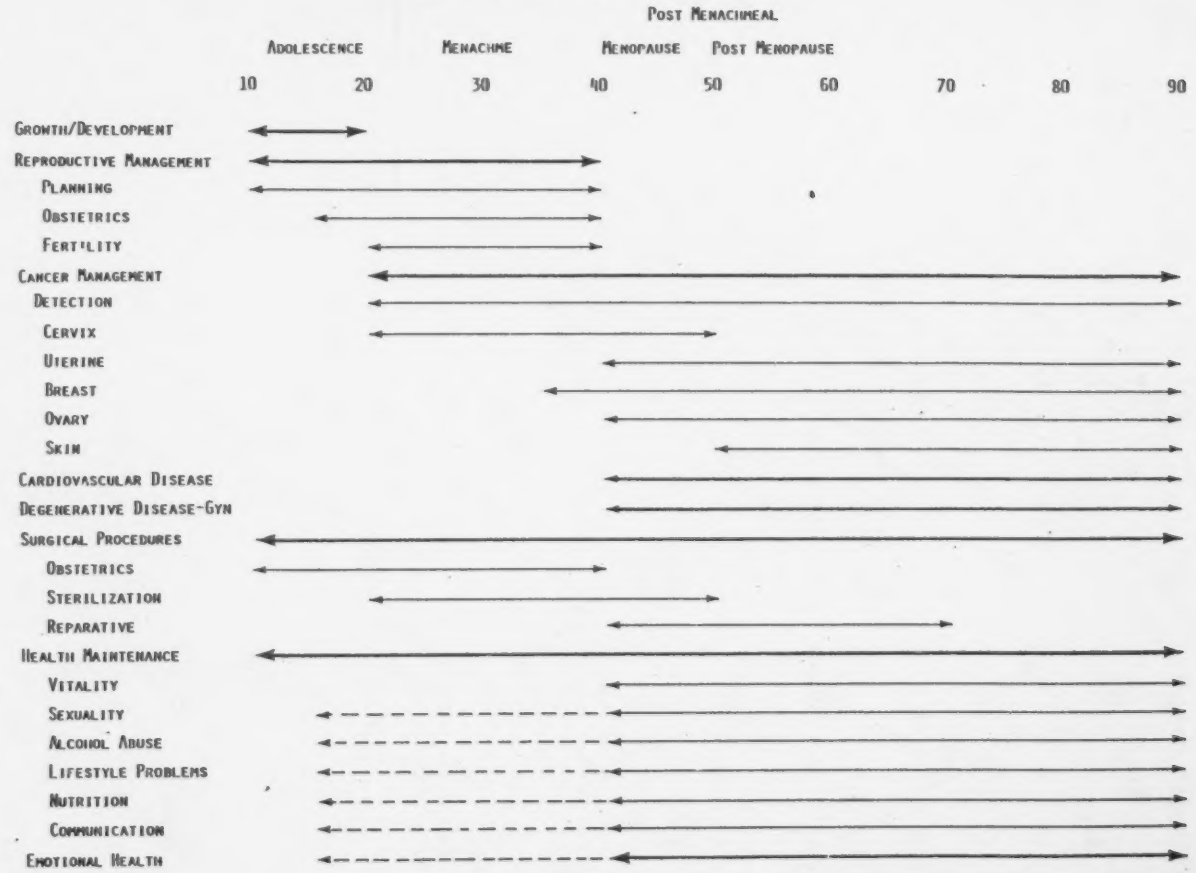
6. Sponsor systems of group interaction for information exchange and dissemination, including interest based guilds and local/regional networks.

7. Develop methods of instruction based upon interactive systems.

8. Monitor and facilitate the application of new knowledge to the practice setting by methods such as on-site consultation teams.

9. Develop a practice analysis kit by which individual physicians can assess their practice patterns and needs to help prepare them for future change.

WOMEN'S HEALTH NEEDS



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Senator HATCH. In closing, we live in an age of unprecedented medical advances and understanding of disease and the causes thereof. Society must continue in its support of programs to help us live longer, more productive and independent lives. Many illnesses that afflict us are preventable. We need to remind ourselves of the wise saying of Benjamin Franklin, an ounce of prevention is worth a pound of cure. I'm a great believer in preventive medicine, medicine that really practices health promotion and disease prevention. I believe that's where we really can find savings in the federal contributions to medical care in this country. I think that statement by Benjamin Franklin is a rule which applies directly to today's hearing.

It's my hope that today's hearing will become a permanent part of the United States Senate's record, and that it will help Americans become educated on the ways to prevent disease in America. I hope my colleagues will read it.

I think we're going to be able to make some of these changes that have been suggested here today and work in some of these areas in ways that haven't been worked on before. It's been a particularly enlightening meeting for me.

I want to thank all of the witnesses who have been here, and I want to thank all of you in the audience who have come to learn about these problems that we have not only in Utah, but across the country as a whole. Hearings like these really make a difference because they get us to start thinking about what the real problems are.

We do have tremendous results sometimes from the Congress. Believe it or not sometimes the Congress really does do a good job. In the area of public health over the last eight or nine years, I believe, we've done a pretty darn good job. We haven't done a totally good job because there are areas we have brought out today where we need to do more.

[Additional material supplied for the record follows:]

88-089 O - 88 - 5

June 6, 1988

The Honorable Orrin G. Hatch
United States Senate
135 Russell Bldg.
Washington, D.C. 20510

Dear Senator Hatch:

I would like to commend you for sponsoring the field hearing on women's health on June 3. As a follow-up to the discussion on breast cancer and mammography I have enclosed a recent consumer survey funded by my company in cooperation with the Utah Division of the American Cancer Society to determine the factors which limit access to screening mammography. Almost 9,000 women responded. I think this is the largest survey ever done anywhere in the nation. We learned several notable things which I think will be of interest to you:

1. Over 90% of women surveyed reported that they know how to do a breast self-examination. The frequency of doing BSE is consistent with national norms. However, our primary care physicians tell us that a woman's skill in doing BSE to detect breast lumps is questionable in many cases.

2. About 40% of women surveyed have had a mammogram in the last five years. This is much higher than the national average of 10%, and is probably due to the high education level of our population, state government-funded breast exam clinics, and the relatively low price for a mammogram in our service area. However, we have no indication that women are getting mammograms at the appropriate ACS-prescribed intervals.

3. The majority of women responding do not realize the importance of screening mammography as a valuable tool in early breast cancer detection. They indicated that their physicians have not encouraged mammography and women thought mammography was useful only when a lump is present.

As a consequence of this input from consumers, Intermountain Health Care is sponsoring the following education and information efforts:

1. Encourage primary care physicians to prescribe mammograms with the same enthusiasm that they encourage pap smears.

2. Explain the difference between screening and diagnostic mammography so that women do not wait until they have a lump to have a mammogram.

3. Inform women about their option to self-refer for a screening mammogram.

4. Educate the public about the cost for a mammogram. Consumers are willing to pay up to $50 for a screen (most Utah hospitals are at or below this amount), but perceive our charges to be twice or three times the actual fee charged. (This is probably because diagnostic mammography charges are $100-150 and consumers confuse the two-tiered price structure).

5. Provide laminated breast self-exam shower cards as a free service to consumers and physicians.

You are in an opportune position to encourage Medicare coverage for screening mammography. Mammography has demonstrated both life saving and health care cost reduction benefits in several independent studies conducted in the United States and Europe over the past 20 years. I think that if the federal government takes the lead on this issue, private insurance carriers will follow. I trust that this important issue will merit your continued attention.

Thank you again for your continuing commitment to serving the women of Utah by focusing on health and child care issues which are of paramount importance to us. If I can be of further assistance, please do not hesitate to contact me.

Sincerely,

Marta D. Clark
Director of Women's Services

MDC:dh
6-0223
Enclosures

BREAST CANCER DETECTION AND TREATMENT OPTIONS

One out of every 10 American women will develop breast cancer during her lifetime. It is the leading cause of death for women 35-55 years old. We do not know what causes breast cancer . . . but it doesn't have to be a killer. When it is detected early, breast cancer can be completely cured 85-90 percent of the time. The earlier breast cancer is detected, the better your chances to save your life and your breast. The **key** is **early detection** - discovering a lump that might indicate cancer as soon as possible - so that treatment options are more flexible and you have greater choice in treatment.

Breast cancer may be the only disease among those frightening and mysterious diseases we hate to think about that we can discover ourselves, either through breast self-exams or by taking the initiative and going for a mammogram. We can take control of breast cancer - learn about it, and detect it early enough to save our own lives.

When breast cancer is detected early, its victims have an 85-90 percent chance of full recovery. Without early detection, the odds drop to 50-50.

These facts aren't meant to frighten you. They're meant to incite you to action. The worst thing you can do about breast cancer is nothing. The following information will help you figure out whether you are at high risk for developing breast cancer, what you can do to detect it early, and what your treatment options are should you develop breast cancer.

Breast Cancer Risk Factors

Primary Risk Factors

- Advancing age - In 1987, about 45 percent of all breast cancer occurred in women over age 65.
- Personal history - Previous breast cancer in a woman herself.
- Family history - Breast cancer in a woman's mother or sister that developed before menopause.

These three factors account for 85-90 percent of your risk for developing breast cancer.

Secondary Risk Factors

- Family history - Breast cancer in maternal grandmother or aunts.
- Fibrocystic conditions - Certain very specific fibrocystic changes in a small percentage of women.
- Pregnancy history - No pregnancies, or first birth after age 30.
- Menstrual periods - Onset of menstruation before age 10 and menopause after age 55.
- Previous cancer - Cancer previously identified anywhere else in your body and especially uterus, ovary, and colon.
- Exposure to radiation - Excessive and prolonged exposure to ionizing radiation, primarily in certain occupations, will increase your risk.
- Alcohol consumption - New research indicates excessive alcohol consumption over sustained periods increases the risk of breast cancer.

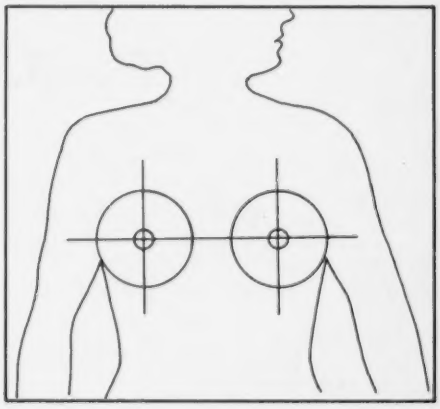
These minor risk factors account for 10-15 percent of your risk for developing breast cancer. Currently, 70 percent of women who are diagnosed with breast cancer do not have **primary** risk factors.

Three Steps to Early Detection

1. Breast Self-Examination

Most breast lumps are discovered by women themselves. A woman's best chance of detecting a breast tumor early is a monthly breast self-examination (BSE). A tumor, once found, will be larger and less curable than if identified early by monthly self-examination. BSE should be done each month five to seven days after your menstrual cycle when swelling and tenderness associated with menstruation have disappeared. If you no longer menstruate, check your breasts on an easy-to-remember date each month. Follow these basic steps:

1. While you are in the shower and your hands and skin are smooth and slippery, move each hand, fingers flat, over every part of each breast. Use right hand to examine left breast; left hand for right breast. Be gentle - no need to poke or prod. You're looking for thickening, hard places, or lumps.
2. Stand in front of a mirror with your upper body unclothed. Look at your breasts while you hold your arms at your sides, then raise your arms over your head. Put your palms on your hips and press, flexing the chest muscles. You're looking for changes in your breasts' shape, a swelling, dimples in the skin, discoloration of the skin, or a change in the way your nipples looks. Don't worry if your breasts don't look exactly the same - most women's don't.
3. Lying on your back with a pillow under your shoulder and your arm behind your head, take your opposite hand, fingers flat, and starting above your collar bone, move your fingers all around your breast, clockwise, in ever-decreasing circles until directly on the nipple. "Flutter" your fingers slightly (this is called "palpation") so that the tissues move underneath them. Circle carefully and thoroughly until you arrive at the nipple. Squeeze it gently between your thumb and finger. You're looking for hardness, lumps, or a discharge from the nipple. Change hands and check your other breast the same way.



Breast Map

Don't panic when you find lumps! Always have a new lump checked by your physician, but remember, about 70

percent of women have breasts that are nodular - lumpy-by nature. These benign lumps may swell or become painful with hormone changes associated with your menstrual cycle. They are not generally considered a greater risk of breast cancer. One way to keep track of the benign lumps unique to your breast is to make a "map" of your breast. Using the diagram above, make a dot, circle, or x where you find a lump the first month. Do it again the next month. Within two to three months you'll have an accurate map of where your lumps are.

2. Professional Breast Examination

Make an appointment for a breast examination by a trained health professional every three years if you are under age 40 and every year if you are over age 40. If you have any of the major risk factors mentioned earlier, you will want to get special instructions on how frequently you should be examined.

Show your care provider any lumps, thickening, or other symptoms you may have noticed when performing your monthly breast self-exam. Also be aware of and mention any discomfort or unusual feeling that isn't like your normal premenstrual tenderness. One-third of cancers manifest by a change in the way your breast feels rather than by a lump large enough to be felt by you or your care provider.

Take this opportunity to ask any questions you might have about your personal risk factors for breast cancer. Review the steps of your monthly breast self-exam to make sure you are doing everything right.

3. Have a Mammogram

A mammogram is a low-dose X-ray of the breast that can be used to detect breast abnormalities and can also identify cancerous tumors up to two years before they can be felt in a self- or physician exam, when the cure rate is over 90 percent. Forty percent of new breast cancers identified in 1987 were identified by mammography alone. The American Cancer Society recommends:

- A baseline mammogram between the ages of 35 and 39 as a reference point for comparing breast changes later in life.
- A mammogram every one to two years if you are between the ages of 40 and 49.
- An annual mammogram after age 50.

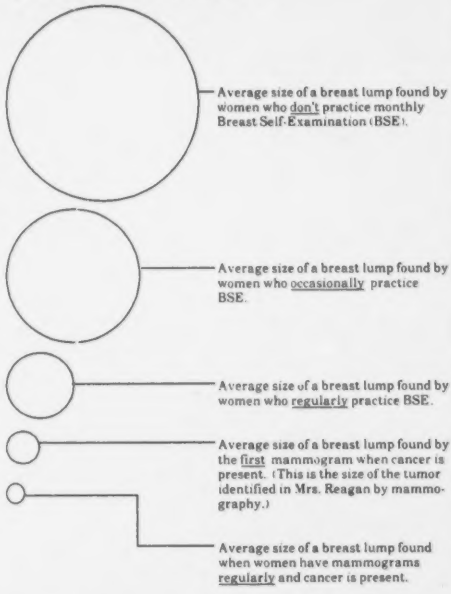
It is helpful to schedule your appointment at a time when your breasts are not swollen or tender - between five and 10 days after your menstrual period. When you go for your appointment, please don't wear deodorant, perfume or powder as it tends to show up on the X-ray. Do wear two-piece clothing, however, so you need only remove your blouse.

A special note about mammography: many women think that a mammogram isn't necessary unless breast symptoms are present. This is not the case. A screening mammogram is recommended periodically for women with no breast symptoms. A screening mammogram can detect abnormalities before noticable physical symptoms manifest themselves. A diagnostic mammogram is performed when symptoms are present. This exam usually includes more views of the breast than a screening mammogram and costs about twice as much.

Women sometimes think they shouldn't have a mammogram if they have had breast implants. This is not the case. Just be sure to tell the technician when you go in for your appointment.

Why Early Detection Pays Off

Early detection saves lives! Practicing monthly breast self-examination, and having periodic professional exams and mammograms means your chances of finding breast cancer and treating it successfully are 85-90 percent. Waiting only ensures that if breast cancer is present, it will continue to grow.


Average size of a breast lump found by women who don't practice monthly Breast Self-Examination (BSE).
Average size of a breast lump found by women who occasionally practice BSE.
Average size of a breast lump found by women who regularly practice BSE.
Average size of a breast lump found by the first mammogram when cancer is present. (This is the size of the tumor identified in Mrs. Reagan by mammography.)
Average size of a breast lump found when women have mammograms regularly and cancer is present.

Used by permission of the American Cancer Society.

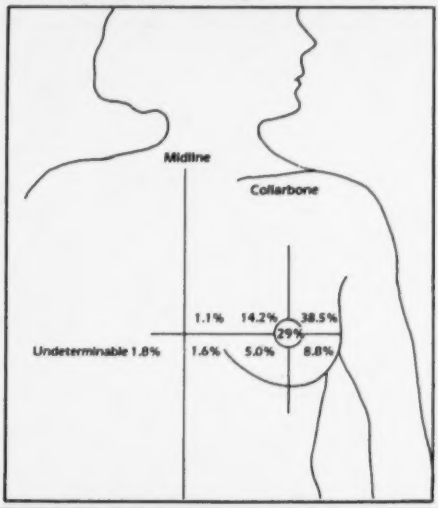
Cysts and Lumps

Cysts can appear suddenly. They often get larger just before menstruation. A cyst will probably hurt (whereas a cancerous lump generally won't), and it will be a little bit flexible in movement like a tiny balloon filled with water. Usually a potentially cancerous lump is hard like a pebble and does not move around when touched. Other visible signs of possible breast cancer include dimpling, scaling, or puckering of the breast or nipples, secretion from the nipples, tenderness or a sensation that feels different from premenstrual tenderness, or changes in the contour of the breast. Such conditions should be examined by your physician without delay.

Where Tumors Most Frequently Occur

This chart illustrates the locations where breast tumors most frequently occur. Malignant lumps are most often found in the left breast (medical research has not yet determined why) and in the upper outer quadrant. It is important to feel the area up to your collar bone and under your armpit as well as your breast.

Locations and Percentages for Most Frequently Occurring Breast Tumors



Dispelling Some Myths About Breast Cancer

1. A bump or blow to the breast will not cause breast cancer.
2. Fondling or caressing won't either.
3. Breastfeeding will not protect you against breast cancer.
4. Breastfeeding will not cause cancer.
5. Breast cancer is not contagious.
6. Caffeine consumption will not cause breast cancer, although it will contribute to breast tenderness in women with fibrocystic breasts.
7. Long-term estrogen use (birth control pills and post-menopausal hormone replacement therapy) does not contribute to increased risk of breast cancer.
8. You can still get breast cancer even though you've had a hysterectomy.

Dispelling Some Myths About Mammography

1. The radiation risk from mammography is minimal. New technology produces 1/10 the radiation of previous equipment. The risk from dying of an undiagnosed breast tumor is much greater.
2. A mammogram is not expensive. Because we are so acutely aware of the value of screening mammography, health care providers in the Intermountain West have led the nation in lowering the cost of a mammogram. Prices at local facilities range from $35-$65, one-third to one-half the price charged nationally.
3. A mammogram shouldn't be painful. During the X-ray your breast will be compressed so that a high-quality picture can be taken. Try to remain relaxed. If you feel discomfort, mention it to the technician. She can suggest positions that will make you more comfortable.

Diagnosing Breast Cancer

All breast lumps must be evaluated by a trained professional. Physical examination and screening mammography are the first two steps a woman can take immediately. Further diagnostic procedures that may be performed include:

- Diagnostic mammogram (additional views of the breast).
- An ultrasound scan may be performed to determine if the lump is solid or filled with fluid (a cyst).
- Needle aspiration - A fine needle is inserted into the lump to see if any fluid can be obtained in a syringe for microscopic evaluation by a pathologist.
- Needle biopsy - A needle is inserted into the lump to attempt to remove a sample of tissue for evaluation by a pathologist.
- Excisional biopsy - Performed under anesthesia, a small incision is made through the breast to obtain a sample of the suspected tumor for evaluation.

A biopsy is the only definative way to determine whether you have cancer or a benign tumor.

Treatment Options

Breast cancer is removed by surgery. In addition, depending on the type of tumor, its location, size and whether or not cancer cells have spread beyond the primary site, additional treatments may also be employed. A brief summary of each is included here.

Surgery:

There are several types of surgery for breast cancer. Surgery can be a "one-step" procedure where a surgical biopsy is immediately followed by one of the surgeries listed below, or a "two-step" procedure, where the woman has a biopsy, which is followed by a second surgery several days or weeks later.

Lumpectomy - Removal of a breast lump, plus a margin of normal tissue around it. This is usually followed by radiation therapy. Frequently the underarm lymph nodes are removed and tested to determine if the cancer has spread.

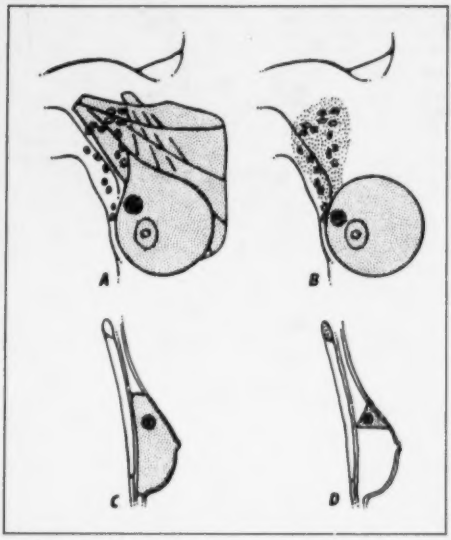
Partial or segmental mastectomy - Removal of the tumor, plus a wedge of normal tissue around it, including skin and the lining of the chest muscles below the tumor. This may be followed by radiation therapy. Underarm lymph nodes are removed and checked for the spread of cancer.

Simple mastectomy - Removal of the breast and closest underarm lymph nodes to check for spread of cancer. It may be followed by radiation therapy.

Modified radical mastectomy - Removal of the breast, underarm lymph nodes and the lining over chest muscles.

Halstead or radical mastectomy - Removal of the breast, chest muscles under the breast, and all underarm lymph nodes.

Different Types of Mastectomies



Shaded areas indicate what is removed in each procedure. The cancer is designated by the blackened lump.

A. **Radical mastectomy**, showing removal of the breast, lymph nodes, and surrounding chest muscle.
B. **Modified radical mastectomy**, showing removal of the breast, lymph nodes, and surrounding tissue but not the underlying chest muscle.
C. **Simple mastectomy**, showing removal of the breast, nipple, and skin, but not the lymph nodes or muscle.
D. **Lumpectomy or segmental mastectomy**, showing removal of the cancer and surrounding tissue.

Source: The American Cancer Society Cancer Book, Arthur I. Holleb, M.D., editor.

Radiation therapy:

Radiation therapy is a primary treatment for early stage breast cancer. It may be used in addition to surgery or chemotherapy. Radiation is aimed at the breast area, and sometimes the area of the underarm and above the collar bone to treat the lymph nodes in those sites. The goal of radiation therapy is to destroy any remaining cancer cells. Treatment usually spans four to six weeks. Several cancer centers are studying the results of combining conservative preservation surgery such as lumpectomy followed by radiation therapy in women who have early breast cancer that has not spread to the lymph nodes.

The early results show that a lumpectomy followed by radiation therapy is as effective in treating early cancer as more extensive breast surgery.

Chemotherapy:

Women whose breast cancer has spread to their lymph nodes or beyond are generally treated with chemotherapy in addition to surgery and radiation so that cancer cells away from the primary tumor are destroyed. Chemotherapy drugs are given by mouth or by injection on a scheduled basis. Chemotherapy may be given alternatively with radiation therapy and a course of therapy is usually completed within a matter of months.

Hormonal Treatment:

Some types of breast cancers rely on female hormones for growth. Hormonal therapy may be used to control the growth of the cancer cells.

After Surgery

Emotional support:

If you have been diagnosed with breast cancer and are undergoing treatment, you may find the recovery process both physically and mentally taxing. In the days following surgery and as you begin to recover, it is important to remember that your life can continue to be as active, rich, and full as ever. Your uniqueness and worth as a person need not be affected by breast cancer surgery - a fact affirmed by those who love you and by other women who have had similar treatment. You can find support from loved ones, nurses, your doctor, a hospital social worker and the Reach To Recovery volunteers of the American Cancer Society. Many trained and caring people are available to support you before and after surgery as your needs dictate. Do not hesitate to ask.

Physical therapy:

You may find relief from the symptoms of breast surgery and companion therapies including swelling, pain, stiffness and muscle weakness or incomplete range of motion in your arm by seeking treatment from a physical therapist. Ask your doctor to refer you to a physical therapist should any discomfort persist.

Breast reconstruction:

Many women may be candidates for breast reconstruction after treatment has been completed. There are several methods of breast reconstruction, including silicone gel implants, and transfer of skin and muscle to the chest from other parts of your body. Depending upon the type of mastectomy done and the post-surgery treatment regimen required, reconstruction may be done either immediately or several months after the mastectomy. Ask you physician to refer you for a consultation with a plastic and reconstructive surgeon to discuss options for breast reconstruction.

INTERMOUNTAIN HEALTH CARE/AMERICAN CANCER SOCIETY
BREAST CANCER CONSUMER SURVEY

Spring 1987
Preliminary Findings
Executive Summary

n = 8866

- 2.2 percent of women surveyed have had breast cancer.

  9 percent were diagnosed in their 30s
  23 percent were diagnosed in their 40s
  30 percent were diagnosed in their 50s
  18 percent were diagnosed in their 60s

- 78 percent of women surveyed have no family history of breast cancer.

- 93.4 percent of women surveyed reported that they know how to do breast self-examination.

  23 percent perform BSE monthly (national rate is 20%)
  44 percent perform BSE every few months
  The remainder perform BSE infrequently

- 3553 (40 percent) of women surveyed have had a mammogram (compared to 10 percent of women nationally).

- If respondents have not had a mammogram in the past five years, the reasons given were: (multiple answers accepted)

Doctor hasn't recommended	56%
Didn't think needed one (no symptoms)	38
Cost	22
Other (procrastination)	12
Didn't know about mammography	10
Concern about radiation	7
Concern about pain	3

- Acceptable prices for a mammogram clustered into three ranges:

Free	21%
$20-30	22
$50	10

INTERMOUNTAIN HEALTH CARE/AMERICAN CANCER SOCIETY
BREAST CANCER CONSUMER SURVEY

Spring 1987

Preliminary Findings

n = 8866

1. Age at time of questionnaire

20-29	239	2.7%
30-34	415	4.7
35-39	1938	21.9
40-49	2281	25.7
50-59	1815	20.5
60-69	1415	15.9
70-79	599	6.7
Over 80	103	1.2
N/R	61	0.7
	8866	100.0

2. Ever had breast cancer?

Yes	198	2.2%
No	8648	97.6
N/R	20	0.2
	8866	100.0

Age when found? (n = 198)

Under 30	3	1.5%
30-39	17	8.6
40-49	46	23.2
50-59	60	30.3
60-69	36	18.2
70-79	14	7.1
Over 80	3	1.5
N/R	19	9.6
	198	100.0

In both breasts? (n = 198)

Yes	34	17.2%
No	158	79.8
N/R	6	3.0
	198	100.0

4a. Family history of breast cancer

Mother		
No h/o breast cancer	8342	94.1%
Had breast cancer	524	5.9
Maternal Grandmother		
No h/o breast cancer	8453	95.3%
Had breast cancer	413	4.7
One or more sisters		
No h/o breast cancer	8404	94.8%
Had breast cancer	462	5.2
One or more maternal aunts		
No h/o breast cancer	7936	89.5%
Had breast cancer	930	10.5
Total number of maternal relations/siblings with h/o breast cancer		
No family h/o breast cancer	6940	78.3%
One female relative	1486	16.8
Two female relatives	315	3.6
Three female relatives	72	0.8
Four female relatives	38	0.4
Five or more female relatives	15	0.2
	8866	100.0

4b. Family history of bilateral breast cancer

Mother		
No h/o breast cancer	8786	99.1%
Had breast cancer	80	0.9
Maternal Grandmother		
No h/o breast cancer	8760	98.8%
Had breast cancer	106	1.2
One or more sisters		
No h/o breast cancer	8774	99.0%
Had breast cancer	92	1.0
One or more maternal aunts		
No h/o breast cancer	8573	96.7%
Had breast cancer	293	3.3
Total number of maternal relations/siblings with h/o breast cancer		
No family h/o bilateral	8329	93.9%
One female relative	476	5.4
Two female relatives	52	0.6
Three female relatives	6	0.1
Four female relatives	0	0.0
Five or more female relatives	3	0.3
	8866	100.0

5. Ever had breast biopsy?

Yes	1400	15.8%
No	7370	83.1
N/R	96	1.1
	8866	100.0

Age at which first biopsy performed (n = 1400)

Under 30	268	19.1%
30-39	339	24.2
40-49	368	26.3
50-59	223	15.9
60-69	88	6.3
70-79	26	1.9
Over 80	5	0.4
N/R	83	5.9
	1400	100.0

Total number of biopsies among 1400 with a positive history

1	913	65.2%
2	266	19.0
3	86	6.1
4	25	1.8
5	12	0.9
More than 5	18	1.3
N/R	80	5.7
	1400	100.0

6. Pregnant before age 30?

Yes	7910	89.2%
No	895	10.1
N/R	61	0.7
	8866	100.0

7. Do you know how to do BSE?

Yes	8281	93.4%
No	484	5.5
N/R	101	1.1
	8866	100.0

If yes, how often do you do BSE? (n = 8281)

At least monthly	1900	22.9
Every few months	3650	44.1
At least yearly	1273	15.4
Less than once/year	1171	14.1
N/R	287	3.5
	8281	100.0

8. Ever had mammogram?

Yes	3553	40.1
No	5279	59.5
N/R	34	0.4
	8866	100.0

If no mammogram in past five years, why not? (n = 5678)
(multiple responses allowed)

Doctor didn't recommend	3168	55.8%
Didn't think I needed	2151	37.9
Cost	1234	21.7
Other*	652	11.5
Procrastination (212)		
Perceived self as too young (56)		
Not concerned (43)		
Didn't know about mammogram	554	9.8
Concern bout radiation	404	7.1
Concern about pain	181	3.2

9. Acceptable price for a screening mammogram

$0	1863	21.0
5	173	2.0
10	521	5.9
15	235	2.7
20	633	7.1
25	998	11.3
30	452	5.1
35	275	3.1
40	375	4.2
45	52	0.6
50	813	9.2
55-75	101	1.1
80-100	160	1.8
Over 100	28	0.0
Any amount	525	5.9
Other	448	5.0
N/R	1214	13.7
	8866	100.0

*See attached list

10. Ethnic origin

White	8684	98.0%
Hispanic	67	0.8
N/R	60	0.7
Asian	33	0.4
Native American	13	0.2
Black	4	0.1
Other	5	0.1
	8866	100.0

11. Education

Grade School	70	0.8%
High School	4125	46.5
1 Year College	1013	11.4
2 Years College	1146	12.9
3 Years College	461	5.2
College Grad	1226	13.8
Advanced Study	633	7.2
N/R	192	2.2
	8866	100.0

12. Employed for wages

No	4834	54.5%
Part-time	1912	21.6
Full-time	1873	21.1
Retired	194	2.2
N/R	53	0.6
	8866	100.0

13. Number of wage earners in household

1	3635	41.0%
2	2819	31.8
More than 2	772	8.7
N/R	1640	18.5
	8866	100.0

14. Marital status

Never married	125	1.4%
Divorced/Separated	418	4.7
Married	7667	86.5
Widowed	611	6.9
N/R	45	0.5
	8866	100.0

OTHER REASONS FOR NOT GETTING A MAMMOGRAM

N=652

212	Procrastination
56	Too Young
43	Don't see value/never a concern
30	Self conscious/embarrassed
30	Pregnant/nursing
23	Insurance limitations
22	Other
18	No doctor/not seen recently
17	Fear of results
17	Not conveniently located
16	Already had one this year/already scheduled
15	Physician exam is sufficient
14	Previous breast surgery/mastectomy
13	No breast symptoms
12	Don't like exams or doctors/expect bad experience
11	Doctor discouraged/not necessary/no value in screening
11	Don't know what a mammogram is
9	Low risk/no family history
9	Didn't know a mammogram was important
9	Doctor recommended appropriate guideline/interval
8	Other health problems
7	Not sure where or how to get
6	No money/can't afford
5	Fear of radiation
5	Breast implants/augmentation
4	Size of breasts/too small, too large
4	Doctor hasn't recommended
4	Fear of pain
3	Not concerned because of previous hysterectomy
3	Too expensive
2	Unreliable/false positives or negatives
2	BSE is sufficient
1	Mammography a nuisance
1	Misunderstood age guidelines
1	Spouse objects
1	Too old
1	Gender of technician
1	Not concerned because of infertility
1	No transportation
1	BSE and physician exam sufficient

AMERICAN CANCER SOCIETY®

INTRODUCTION

Breast cancer is the most common cancer that occurs among women in Utah. Fortunately, it is also one of the most treatable cancers *if it is detected early*. It is our goal to decrease the number of women who die from or are otherwise affected by this disease. Therefore, we are constantly seeking information that can help us to improve programs for the early detection of breast cancer. This survey is being sponsored by the Utah Division of the American Cancer Society and Intermountain Health Care, Inc., for scientific purposes and as a community service. The results will be shared with all medical professionals who are concerned with the detection and treatment of breast cancer, regardless of the hospitals with which they are associated.

The following set of questions is designed to provide information about the risk of breast cancer among women in Utah and to help us tailor educational programs and breast cancer screening to better meet the needs of women in the state. We are not able to ask every woman these questions; instead, we are carefully selecting a sample of women who can provide representative answers. You have been selected as part of the sample group. Please complete the survey and return it in the self-addressed, stamped envelope we have provided. Your answers are very important because even a few missing responses can make the survey inaccurate. However, your participation is entirely voluntary. It should take less than 5 minutes to answer all of the questions. We appreciate your help in this effort.

Some of the questions are of a personal nature. However, your answers are completely anonymous — the woman who fills it out cannot be identified. The information you provide will be combined with that of other women in the sample and analyzed. The results will be used to plan future breast cancer screening programs and to better understand breast cancer.

INSTRUCTIONS

Please read and answer each of the 14 questions in order. Print your answers clearly in the space provided, or clearly check or circle the appropriate answer. Some questions ask that you select responses from a list of possible answers — please read these questions carefully, as some will require *only one answer* while others will ask you to circle *as many answers* as you think apply.

If you do not know the answer to a question just put a question mark — "?" — in the answer space or next to the question. If you do not wish to answer a particular question just leave it blank.

QUESTIONS

1. What is your age? _____

2. What is your zip code? _____

3. Have you ever had breast cancer? No( ) Yes( )

   If yes: - how old were you when it was first found? _____
   - how long has it been since it was first found? _____
   - was it in both breasts? No( ) Yes( )

4. Have any of your close female *blood relatives* (mothers, sisters, maternal grandmother, or maternal aunts) ever had breast cancer? To the best of your knowledge, did any of them have it in both breasts? (Check off the proper boxes in the following table. If more than one sister or aunt had cancer, write the number that had breast cancer in the box. Count each person only once, even if they had breast cancer more than one time.)

	Those with breast cancer of any sort	For those listed in the first column, those who had cancer in both breasts
Mother	☐	☐
Maternal grandmother	☐	☐
Sisters (write the number)	☐	☐
Maternal aunts (write the number)	☐	☐

5. Have you ever had a breast biopsy (a procedure in which tissue is removed from your breast, either surgically or through a needle, then analyzed in a laboratory for cancer or other problems)?

No ( ) Yes ( )

If yes: - how old were you when you had your first breast biopsy? _____
- how many breast biopsies have you had? _____

6. Were you pregnant before you were 30 years old? No ( ) Yes ( )

7. Do you know how to do a breast self-exam? No ( ) Yes ( )

If yes, how often do you actually do them? (Please circle one response that best describes your practice)

a. At least monthly
b. Every few months
c. At least yearly
d. Less than once a year

8. Have you ever had a mammogram (an X-ray of the breast)? No ( ) Yes ( )

If yes, how long ago was the last one? (Please circle one response)

a. within the last year
b. within 1 - 2 years
c. within 2 - 5 years
d. over 5 years ago

If you have never had a mammogram or have not had one within the past 5 years, please circle the reasons that you have not (circle all that apply)

a. Didn't know about them
b. Knew about them, but didn't think I needed one
c. My doctor has not recommended that I get one
d. Concern about radiation (X-ray) exposure
e. Concern about pain
f. Cost
g. Other: _____

9. If you had no symptoms or other evidence that might indicate breast cancer and you had to pay for a mammogram to be more certain, how much would you be willing to pay? _____

10. Please circle the one response that best indicates your race:

a. White
b. Hispanic/Spanish surname
c. American Indian
d. Asian or Polynesian
e. Black
f. Other

11. What is the total number of years of formal schooling that you have completed? (grade school through high school is 12 years) _____

Please list the highest academic degree you have obtained: _____

12. Are you employed for wages?

No ( )
Yes: Part-time ( )
Yes: Full-time ( )

13. How many wage earners presently live in your household? _____

14. Please circle the one response that best indicates your present marital status:

a. Never married
b. Divorced/separated
c. Married
d. Widowed

1987 MAMMOGRAMS

HOSPITAL	VOLUME BY QUARTER 1Q	2Q	3Q	4Q	1987 TOTAL	PERCENT OF TOTAL
CASSIA	142	156	100	137	535	2.0%
POCATELLO	220	251	202	350	1,023	3.8%
EVANSTON	104	120	192	228	644	2.4%
LOGAN	454	560	579	726	2,319	8.7%
MCKAY-DEE	701	787	836	998	3,322	12.4%
LDS HOSPITAL	960	1,163	1,118	1,279	4,520	16.9%
COTTONWOOD	870	914	959	940	3,683	13.8%
ALTA VIEW	322	429	437	547	1,735	6.5%
AMERICAN FORK	284	403	254	426	1,367	5.1%
OREM	82	110	65	95	352	1.3%
UTAH VALLEY	893	1,087	719	1,586	4,285	16.0%
WASATCH COUNTY	0	0	60	95	155	0.6%
SANPETE	0	0	33	33	66	0.2%
SEVIER	32	123	83	178	416	1.6%
DELTA/FILLMORE	0	15	43	197	255	1.0%
VALLEY VIEW	62	158	116	138	474	1.8%
DIXIE	364	401	406	463	1,634	6.1%
TOTALS	5,490	6,677	6,202	8,416	26,785	100.0%

1985	1986	85-86%	1987	86-87%
11,068	16,953	53.2%	26,785	58.0%

Report to the Senate
Labor and Human Resources Committee

on

"Cancer Detection in Women and
Other Health Care Concerns"

June 3, 1988

by

The Junior League of Ogden
Nikki H. Lovell, Chairperson
"Woman to Woman" Committee

The Junior League of Ogden is an organization of women committed to promoting voluntarism and to improving the community through the effective action and leadership of trained volunteers. Its purpose is exclusively educational and charitable.

JUNIOR LEAGUE OF OGDEN
POSITION STATEMENT ON WOMEN

The Junior League of Ogden is committed to ensuring that women have fair and equal economic, political and social opportunities and will advocate to see that such opportunities are accessible.

Report of Junior League of Ogden

In January of 1986 the Association of Junior Leagues along with the Allstate Insurance Company held the first training for the "Woman to Woman" project. As the delegates from Utah, we were astounded ourselves to see and hear the surprise from other states over Utah's seeking information on women and alcohol. It was assumed by people outside our state that we wouldn't or didn't need this kind of program. We became part of a pilot project; there were 30 leagues originally involved.

After our training our first course of action was to return home and put together a community board interested in this issue. Our next task was to survey our community on perceptions of services available to women for the treatment of substance abuse. Those to be surveyed were the "gatekeepers," people women go to for help. We interviewed law enforcement, physicians, clergy, social agencies, treatment centers and political entities. Our own survey consisted of 60 people; of those, tive were women. Our first discovery was that decisions on needs for women are basically being made by men.

The objectives of the "Woman to Woman" project are:

Phase I:
1. Document existing alcohol-related services for women.
2. Assess the level of awareness of those services by community professionals who work with substantial numbers of women.
3. Report these findings to the community.

Phase II: Conduct a public awareness and education effort.

Phase III: Develop model programs for women based upon survey findings.

The tindings in Utah were no ditferent than the findings of the other 29 sites in the nation.

FINDING #1

The Need for Childcare for Women in Treatment

Many studies report that a substantial proportion of chemically dependent women have children and that many more women than men entering treatment have the major caretaking and financial responsibility for their children. The inability to care for their children is a major source of pain for chemically dependent women (eg. Rosenbaum, 1981), and they worry about their children as a major factor in seeking treatment.

A question to be answered is why should or would a woman risk losing her children to gain access to treatment. Many times the fear of putting children into foster care during treatment is whether the mother then has a right to have them back. Admitting that abuse or

neglect may have occurred prior to treatment may jeopardize her chances of having her children returned after treatment. This may be a real or a misperception, but it is a question that must be answered for women.

If you suffered from another disease such as cancer, upon remission of that disease there would be no question of the return of your children. Why then is there a problem for women who upon the remission of alcoholism must face not having their children returned? We would support efforts to prevent this discrimination of diseases.

Childcare must also address the needs of children of a chemically dependent parent. Children of alcohol and drug dependent parents are at a greater biological risk for developing the disease of chemical dependency. Besides the biochemical/genetic influences there also exists a psychological pull towards addiction. To provide a program of recovery for these children may prove to be the truest form of prevention.

FINDING #2

The Need for Education for Women About Alcohol Use

The problems associated with women and alcohol have received considerable attention during the past ten years in part because of the increased awareness of the lack of research on this topic. As research and knowledge on this subject has surfaced, methods for prevention and awareness strategies are just beginning to appear.

The Junior League of Ogden has looked at this area and this year sponsored the first women and alcohol conference open to the public. Our conference received much public support. Along with our success we were told of four women who referred themselves for treatment as a result.

The Junior League of Ogden is also a pilot project for alcohol awareness in the federal workplace. Since we began about a year ago our Improvisational Troupe has performed for several worksites. Through this endeavor we have verified the fact that women are unaware of the effects of alcohol on the female body. We have not had an audience that could tell what services or how to get a friend into help. It was noted by a professional in our audience that "even when women know when and where to come that still they are reluctant." She had more than once found a woman crying outside her office afraid to enter alone. This is the reason for the "Woman to Woman" project--women reaching out to other women with not only the education of the problem but with information of the resources available. To make this even more of a reality our League helped in the "Survival Guide of Women's Resources." Our guide has been recognized as a model for communities throughout the nation. We feel that since women seek help more readily than men that the information and education must be made available to them.

FINDING #3

The Need for Intormation and Referral Services for Women

(The Utah survey supported outpatient services for women tied with intormation and Referral.) There are now over 80 leagues participating in the "Woman to Woman" project. These leagues will continue to educate and inform women of the issues about alcohol. These programs will in turn bring more women out in the open that need help. It is only fair to them that services are available and accessible to them. These services should not just include women in existing programs originally designed to serve men but should be programs specifically designed to address the gender-specific needs of women. For this reason the Junior League of Ogden under the advisement of the Association of Junior Leagues continues to support these advocacy issues:

1. ADAMAHA block grant set asides for alcohol services for women.

2. Women's Health legislation includes information about the gender-specific impact of alcohol on female health and includes provisions for gender-specific alcohol and drug abuse prevention and education, as well as treatment that meets women's needs.

3. Prevention programs funded with monies from the Drug-Free Schools and Communities Act of the Anti-Drug Abuse Act of 1986 that includes specific information for girls and women, concerning the short- and long-term impact of alcohol on females' health and the social patterns, social consequences and at-risk profile of female alcohol abusers.

As a special concern for those of us from Utah, a state that has a significant problem with prescription abuse, we ask that all forms of substance abuse be addressed as it pertains to women. We also recognize that physicians' awareness and education needs to be an ongoing process as it relates to these issues. We recognize the need for drugs as a benefit but must now recognize the danger that can and does occur in a society that looks for happiness from chemicals.

We recognize the increased use of alcohol by our teenagers. With the use of alcohol and acceptance by our teenagers of the drug, we note young girls now beginning to drink equally with boys. This is a serious concern for the future. Without knowledge and education our country will sutfer long-term consequences which we are already seeing in the form of teenage pregnancy, fetal alcohol syndrome and effects, suicide, and accidental deaths.

These are issues that did not happen overnight. It will take time. We must continue efforts and not stop with the first few successes. Woman to Woman will and has evolved with the new findings and information. This year the Association of Junior Leagues was a

co-sponsor of the National Association of Children of Alcoholics Fourth Annual Conference. In September we will co-sponsor a conference on Woman and Alcohol in Washington, D. C. This is only the beginning. We hope to continue in our effort.

We submit to record these opinions and support expansion of health care services for women in the prevention and treatment of substance abuse.

Note: Due to printing limitations and in the interest of economy, certain additional material, including "Woman To Woman Survey Report, Fall 1986," submitted for the record was retained in the files of the committee.

Junior League OF OGDEN

WOMAN TO WOMAN

Objectives:

Phase I: 1. Document existing alcohol-related services for women.
2. Assess the level of awareness of those services by community professionals who work with substantial numbers of women.
3. Report these findings to the community.

Phase II: Conduct a public awareness and education effort.

Phase III: Develop model programs for women based upon survey findings.

Findings:

The three most needed services for women cited by those interviewed were:

1. Arrangements for child care for women in treatment
2. Education for women about alcohol use
3. Information and referral services for women who need help

In the Junior League of Ogden survey, outpatient treatment services for women tied with the third need listed above. Otherwise the Utah results were the same as these three national pilot survey findings.

Advocacy Issues:

1. ADAMAHA block grant set asides for alcohol services for women.

2 Women's Health Legislation should include information about the gender-specific impact of alcohol on female health and it should include provisions for gender-specific alcohol and drug abuse prevention and education, as well as treatment that meets women's needs.

3. Prevention programs funded with monies from the Drug-Free Schools and Communities Act of the Anti-Drug Abuse Act of 1986 should include specific information for girls and women, concerning the short and long-term impact of alcohol on females' health and the social patterns, social consequences and at-risk-profile of female alcohol abusers.

Action Agenda:

With ADAMAHA assistance the grass roots WOMAN TO WOMAN Collaboration in Utah has achieved the following since 1986: sponsored the first Utah substance abuse conference focused upon the needs of women, assisted in publishing a nationally acclaimed resource guide, founded a model improvisational theatre troupe for educating the workplace and college campuses, produced thousands of trained volunteer hours and donated dollars in partnership with private enterprise and governmental agencies, produced research used as a basis for founding a women's treatment facility with preschool child care. Continued federal support is essential to address this problem for women nationally.

Briefing Participants: Nikki Lovell, Neta Wood and Carol Gaskill

TWENTY-FIVE EIGHTY JEFFERSON AVE. OGDEN, UTAH 84401 801-393-2540

UTAH STATE UNIVERSITY · LOGAN, UTAH 84322-7000
COLLEGE OF EDUCATION

DEPARTMENT OF HEALTH,
PHYSICAL EDUCATION
AND RECREATION
801-750-1497

February 1, 1988

Barbara Robinson
Junior League of Ogden
2580 Jefferson
Ogden, UT 84401

Dear Ms. Robinson:

I recently attended your "Woman to Woman" Conference in Ogden and I thought it was excellent. The Junior League is to be commended for their sponsorship of this national program and your Ogden group for the work you are doing with this program.

In reading through the pamphlets in the registration packet, I thought how appropriate they would be for the stucents in my Women and Health class. I do not have time to cover the area of Women and Drugs adequately and so appreciate any written material I can get to receive twenty copies of the three, "Woman to Woman, pamphlets, "The ABC's of Alcohol Education for Women," and the one titled, "Alcohol and You"? I am somewhat reticent about asking for multiple copies of materials, but these pamphlets would reach an important and appropriate audience.

As Chairman of the State Policy Board on Alcoholism and Drugs, I am cognizant and concerned about alcohol and other drug problems among women, I am also aware of the need to increase treatment services for women. Our Board does keep this in mind.

Again, I want to compliment you on an excellent conference and your excellent contributions to the community.

Sincerely,

Janice Pearce, Ph.D.
Chairman, State Policy Board
on Alcohol and Drugs

cc: ✓ Nikki Lovell

Congratulations to you too. Tried to reach you to find out if I was sending this to the right person. I do not know a lot about the Program. When I received it

U.S. DEPARTMENT OF COMMERCE
National Oceanic and Atmospheric Administration
National Weather Service Western Region
P. O. Box 11188 Federal Building
Salt Lake City, Utah 84147

September 24, 1987 W/WR1x2:EM

Woman-to-Woman Cast
Junior League of Ogden
2580 Jefferson Avenue
Ogden, UT 84401

Dear Carol, Nikki, Paula, Kelly, Willi, Nolene, and Jareta,

Even though I didn't have the opportunity to meet all of you, thank you all for your efforts in putting together the Woman-to-Woman program. The presentation you gave to the Federal Women's Program Mangers Committee of Utah was funny, to-the-point, thought-provoking, and well-done. While I expected the topic to be interesting, I didn't expect it to be entertaining! I was impressed by the acting ability displayed in the skits.

Discussions with cast members afterwards also were worthwhile. The small group discussions were where most of us picked up the information we had expected to be lectured on during the presentation.

I don't know why more women didn't attend. Some of the members have been forbidden to travel due to tight agency budgets. Others might not have realized that a presentation on alcoholism doesn't have to be a dry lecture filled with statistics and lacking in hope. In any case, they missed out on a wonderful program. Thank you for taking the time to share your work with us.

Sincerely,,

Elizabeth Morse

Elizabeth Morse
FWPMC Chairperson

DEPARTMENT OF THE NAVY
NAVAL PLANT BRANCH REPRESENTATIVE OFFICE
(STRATEGIC SYSTEMS PROJECT OFFICE)
SUNNYVALE (DETACHMENT A)
HERCULES INCORPORATED
P.O. BOX 157
MAGNA, UTAH 84044-0157

IN REPLY REFER TO:
28 Sept 1987

Nicky Lovell
Junior League of Ogden
2580 Jefferson
Ogden, UT 84401

Dear Nicky,

I'm looking forward to having you and your troop present your Woman to Woman program to us for our Federal Women's meeting on November 18. The meeting will begin at 1:30. Let me give you a little background.

We are civilians, for the most part, employed by the Navy to oversee the building of TRIDENT missiles. We have about 20 women who work at Hercules, one who works in Clearfield, and myself, associated with Morton Thiokol. We are secretaries, transportation and contract specialists, quality assurance inspectors, and administrative assistants.

We will be meeting in a conference room in the Navy area of Hercules' Arbor Park complex located in downtown Magna. Hopefully the enclosed map will show you how to find us. I always use the Smith's store as a landmark.

There will be a guard inside the foyer; you will need to report to her. She will alert the Navy office of your arrival so you can be signed in. An escort will be required while you are in the building.

Thanks for your willingness to meet and address our group of Federal Women.

Sincerely,

Lana Billings
(801) 863-3731
FW FEDERAL WOMEN'S
PC PROGRAM COORDINATOR

DEPARTMENT OF THE NAVY
NAVAL PLANT BRANCH REPRESENTATIVE OFFICE
(STRATEGIC SYSTEMS PROJECT OFFICE)
SUNNYVALE (DETACHMENT A)
HERCULES INCORPORATED
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IN REPLY REFER TO:
12713
24 Nov 87

Nikki Lovell
Junior League of Ogden
2580 Jefferson
Ogden, UT 84401

Dear Nikki,

Thanks! You did a great job! Nearly everyone in attendance commented to me on the program and every comment was favorable. It really opened up some discussion among various groups around the office, which is great.

There were a couple of negative comments, directed at my planning rather than your program. I'll pass these on and maybe they'll help another group. From the women: Some wished their supervisor hadn't been there. They felt they could have opened up and asked more specific questions. From the supervisors: They wished all employees, male and female, had been there. I'm not sure how to accommodate both short of segregating everyone and making two presentations.

Our commander called to thank me for arranging such a high-quality program for our Federal Women. [illegible] the first time he's participated in one of our meetings and, thanks to you guys, he has something concrete to back up a belief that it's a valuable program (which it is) and I'm sure we'll get more support from him in the future.

Reimbusement for your mileage is being processed and hopefully will be in the mail soon. Thanks again for your time and for the excellent presentation.

Sincerely,

Lana

Lana Billings
FW FEDERAL WOMEN'S
PC PROGRAM COORDINATOR

DEPARTMENT OF THE NAVY
NAVAL PLANT REPRESENTATIVE OFFICE
SUNNYVALE DETACHMENT (DETAI
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IN REPLY REFER TO:

12713
Ser 1612
November 20, 1987

Junior League of Ogden
2580 Jefferson Avenue
Ogden, UT 84401

Dear Ms. Lovell:

Thank you for bringing your troop to our office yesterday to share your "Woman to Woman" program. It was an excellent presentation bringing to light the situations in a woman's life that may cause difficulty. This has helped us become more aware of potential problems and ways we can help, both as supervisors and fellow employees.

The way you presented your information was both entertaining and educational. I was impressed with the quality of the program and would highly recommend it to other groups. I commend you for what you are doing.

Sincerely,

G. L. BROWN
LCDR, USN

Senator HATCH. Again, I want to thank everybody concerned. And with that we will recess these hearings until further notice.

[Whereupon, at 12:15 p.m., the hearing adjourned subject to the call of the chair.]

88-089 (144)